# Relationship Between Patient Satisfaction, Quality of Life and Quality of Care for Cancer Patients: a New Approach for Application in Ambulatory Specialised Care

# **THESIS**

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Abstract

### **Abstract**

The aim of this pilot study is to qualitatively determine whether patient satisfaction (PS) and quality of life (QOL) can be used to evaluate patient oncological quality of care (QOC) in a single outpatient unit. The study also examines how patients in a single oncological outpatient unit in Germany interpret the quality of care in the previous healthcare model as compared to the care provided by the new ASC model.

Ambulatory Specialised Care (ASC) was established by law in the German healthcare system with the objective of improving the outpatient care of rare and severe diseases and providing an extensive range of services. The first oncological application of ASC was gastrointestinal cancer in June 2014. How and whether ASC is beneficial for patients undergoing care in outpatient practices is yet to be determined.

Every cancer patient defines oncological quality of care differently. This is because each patient has individual experiences and develops unique ideas about what elements of the healthcare system are beneficial. This study therefore views patient satisfaction as being of central importance in the understanding of oncological quality of care. This idea has been considered in quantitative studies with larger sample sizes, which show that not only are oncological "hard" endpoints such as response rate, mortality, and disease free survival the basis for oncological quality of care, but also quality of life and patient satisfaction (Kleeberg et al., 2005). This study does not focus on the "hard" endpoints of oncological therapy, as these are not quantitatively determinable in single outpatient units because of the small number and heterogeneity of patients.

The methodology of the research consisted of a single case study, the object of which was a single outpatient unit. Twenty participants, ranging from 55 to 85 years of age, all suffering from gastrointestinal tumours participated in the study. Semi-structured interviews and generic questionnaires (analogous to SF-12) were conducted with two separate groups of ten patients. These patients were undergoing treatment in the same outpatient clinic at the time of their interviews. The first group of patients was receiving care under Germany's previous healthcare system. The second group was receiving care under the new ASC model. Both groups of patients were first interviewed to assess patient satisfaction and two weeks later they completed questionnaires assessing quality of life. Data analysis and synthesis based on answers from the semi-structured interviews were used

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to evaluate the oncological quality of care. The linking of results was done through triangulation.

The results of the study were the following: The comparison of the two patient groups revealed that "trust in the doctor", patient activation and "would the patient recommend the medical practice" were key topics for patients and played a major role in patient perceptions of oncological quality of care. Most of the patients show concordant valuation of patient satisfaction and quality of life. A patient's individual deviating valuation between interview and questionnaire produces additional indications. A better validation of PS compared to QOL may express "patient acceptance of disease" and "appreciation of the oncological treatment" and vice versa.

The group of patients undergoing care under the ASC model differed from the group without ASC in that they better rated the degree to which they were informed about diagnosis, treatment options, possible side effects of therapy and alternative treatments. This can be explained by the fact that a more comprehensive information network exists in the ASC system. In both groups, cooperation between the treating doctor and other institutions as well as the coordination of waiting-times and appointments were highly valued. These aspects are some of the direct objectives of ASC.

As a contribution to knowledge, the results of this qualitative case study indicate that the evaluation of patient satisfaction and quality of life in a single outpatient unit can be used to assess the oncological quality of care. Since the start of implementation of the ASC, the QOC seems to be influenced only marginally. ASC appears to result in better informed patients; however, the study did not identify any major differences in the quality of life experienced by patients in the two healthcare models. The identified key topics are similar to those highlighted in previous quantitative studies. The researcher would add that a qualitative approach is an attribute to studies that are primarily quantitative.

Based on the results of this study, the further development of a practicable tool could be a new way to determine the QOC in single outpatient units. Further studies are needed to compare other medical institutions using the chosen qualitative approach to evaluate the oncological quality of care. A rapidly available tool to estimate the PS in a single outpatient unit would support the continuous quality improvement and be beneficial for patients with tumours.

Abstract

# **Keywords:**

oncological quality of life, qualitative semi-structured interview, oncological patient satisfaction, oncological quality of care, single outpatient unit, ambulatory specialised care.

# **Declaration of original content**

I declare that the work in this thesis was carried out in accordance with the regulations of the University of Gloucestershire and is original except where indicated by specific reference in the text. No part of the thesis has been submitted as part of any other academic award.

Any views expressed in this thesis are those of the author and in no way, represent those of the University.

Ruth Anna Weber Date: 01 August

2019

Signature

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Dedication

# **Dedication**

This thesis would not exist without the continuous help and support of a number of people who contributed their suggestions and advice. First of all, I would sincerely like to thank both my supervisors of the study. Dr. Francisca Veale and Professor Michael Erhart who provided extremely valuable advice and dedicated much personal effort to this project. Furthermore, I would like to thank Claire Manning; her support enabled me to start this project written in the English language along with Finn-Frederik Harnisch's computer knowledge. I also should express my gratitude to my teacher, Dr. Philippa Ward, who connected me to the academic world and supported me with advice whenever needed.

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Abbreviations 14

#### **Abbreviations**

APA American Psychological Association

ASC Ambulatory specialised care

ASCO American Society of Clinical Oncology

CAQDAS Computer aided/assisted qualitative data analysis software

CC Comparative case

CCC Comprehensive cancer centres
CIT Critical incident reflection

CQI Continuous quality improvement

G-BA Federal Joint Committee
GP General practitioner
GT Grounded Theory

HRQOL Health-related quality of life
IOM American Institute of Medicine
KPF Kölner Patient Questionnaire

NHS National Health Service

NPCRDC National Primary Care Research and Development Centre

NVIVO QSRinternational.com
PRO Patient-related-outcome

PS Patient satisfaction

QDA Qualitative data analysis

QI Quality indicator
QM Quality management

QOC Quality of care
QOL Quality of life

QOPI Quality oncology practice initiative

RAND Appropriateness method –RAND/UCLA

UCLA University of California, Los Angeles

UK United Kingdom
US United States

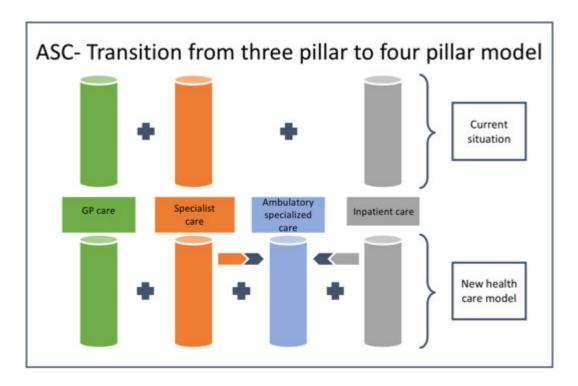
WHO World Health Organisation

# 1. Introduction

This research qualitatively investigates the relationship between patient satisfaction, quality of life and the quality of care for patients undergoing oncological treatment in a single outpatient unit. The qualitative approach used in this study focuses on Donabedian's (1980) Donabedian (1980) quality management aspects of structure-, process-, and outcome quality. Additionally, this research expands the limited body of knowledge relating to the perceptions of quality of care among patients who are being treated under the new ASC healthcare model.

Up until 2012, the healthcare model in Germany was based on three pillars: outpatient units with general and specialised practitioners and inpatient treatment in hospitals. Recently, however, the German medical system has changed to incorporate the ASC model. ASC consists of a collaboration between physicians of different fields and acts at the interface of the three pillars mentioned above (see FIGURE 1: TRANSITION FROM THREE TO FOUR PILLAR MODELS IN HEALTH CARE (ADAPTED BY JAECKEL). The new ASC system is only for patients with severe and rare diseases and provides extended services such as close cooperation between specialists from inpatient and outpatient care to improve medical supply (under the conditions of 26.07.2014). To comply with very high-quality standards, a team of specialists and psychotherapists are permanently available. All costs are covered out of budgets for office-based care. The aim of ASC is to ensure a smooth transition between home, hospital and ambulatory care for patients with severe illnesses. While it was officially launched in February 2012, ASC was only established for gastrointestinal cancer in the oncological outpatient unit at the centre participating in this study in July 2016. Ambulatory specialised care is a service offer oriented to actual needs. To avoid overuse, underuse or misuse, a fair distribution and a structured framework are required. The equitable participation of all involved doctors can lead to an improvement of QOL, PS and QOC for patients. ASC is of political and social importance, and the challenge will be to provide interdisciplinary networking and quality improvement. Because it is such a new approach, very little research has focused on ASC up until now.

FIGURE 1: TRANSITION FROM THREE TO FOUR PILLAR MODELS IN HEALTH CARE (ADAPTED BY JAECKEL)



Many quantitative studies have shown that there is a relationship between QOC, PS and QOL (Kleeberg et al., 2005). Patients with chronic and long-term illnesses require comprehensive care that is based both on their medical needs and their personal expectations (Biermann & Küchler, 1999). There is a strong need to establish relationships based on PS and QOL to receive better health outcomes (Kleeberg et al., 2005). Both cancer patients and oncologists have become increasingly interested in improving the quality of patient care that encompasses issues such as PS and QOL (Baumann, Nonnenmacher, Weiß, & Schmitz, 2008). As Lohr and Schroeder (1990) elaborate, the quality of patient care must continue to improve. A cancer diagnosis and oncological treatment are psychological burdens for patients, who require information and transparency about their illnesses to attain optimal health outcomes (Aaronson, 1989; Bullinger, 1989).

Two main research questions are addressed in this thesis: Firstly, is it possible to assess the QOC of patients in one single outpatient unit by evaluating QOL and PS? Secondly, how are patient evaluations of QOL and PS affected by the new German health care model of Ambulatory Specialised Care (ASC)?

#### Empirical structure of the research

This thesis contributes to the field of quality assurance and is divided into seven chapters. Chapter 2 contains the literature review. Chapter 3 presents the methodology, explaining the philosophical point of view of the research and derivation

of the paradigm. In chapter 4, the concept and design of the study, the research tools, and the analysis methods are described. Chapter 5 follows with the results of the study. Chapter 6 contains a discussion of the results. In chapter 7, a summary and conclusions are provided.

# 1.1 Focus of the project

Maintaining and improving quality of life are the most important treatment objectives for patients with chronic and long-term tumour diseases (Smith et al., 2012). As Smith et al. (2012) pointed out, the many needs of cancer influence their daily lives; therefore, for a definition of quality of life, subjective well-being, patient satisfaction and quality of oncological care are essential. QOL must be redefined in a way that incorporates the multidimensionality of the concept (Bullinger, 1991). Bullinger (1991) explains this concept in terms of physical and mental condition, and of social relationship.

The concept of quality is generally defined by how good a product or service is, by added value in everyday life and in a philosophical context (De Santis & Steininger, 2014). While studies have implemented the theory of quality of life since the 1960s, the distinction between quality of life and health-related quality of life (HRQOL) has only been recognised since the 1980s. The concepts are used interchangeably in the literature. Calman (1984) stated that quality of life applies to all areas of life such as psychological, social and economic well-being, especially with regard to illness and treatment of that illness. HRQOL focuses on an individual's health or illness status. Therefore, HRQOL shows the differentiation between aspects of quality of life and the relationship with health. Additionally, QOL goes beyond health and relates to physical, psychological functioning and social environment (Treurniet, Essink-Bot, Mackenbach, & van der Maas, 1997).

In brief, the definition of health by the WHO Group (1995) states: "Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity". The WHO definition provides a broad definition of health as the perfect status of physical function, mental status and social well-being (explained on p. 37). This is elaborated upon in section 1.4.1.

A cancer diagnosis will affect one in two people (born in 1960) at some time in their lives (Ahmad, Ormiston-Smith, & Sasieni, 2015). In addition to this, today, people are living longer with their oncological diseases. The affected parties require active participation in their complex treatment processes. As a result, long-term, coordinated and cross-sectoral care will move into focus in society

(Neumann et al., 2007). The importance of this research topic as a perspective for oncological health research and for the society lies in:

- —Firstly, the focus in the future of health service research aligned to patient-centredness requirements, patient perspectives and their needs.
- —Secondly, consideration of the social environment, familial predisposition and development of cancer health disparities.
- —Thirdly, cross-functional projects and quality of health care processes and their results.
- —Fourthly, development and implementation of instruments to determine the quality of outcome parameters in patient care such as patient satisfaction (PS) and quality of life (QOL).

This study aims to investigate the quality of oncological care in an outpatient unit that is organised by a new supply structure called Ambulatory Specialised Care (ASC), which was established in February 2012 in Germany. This research seeks to uncover to what extent the introduction of ASC optimises the quality of oncological care in the outpatient unit and to what extent it provides tangible benefits for patients.

In the following chapters, the quality of oncological care in a single outpatient unit will be evaluated, based on a qualitative determination of quality of life and patient satisfaction. Up to now, these parameters have mainly been recorded quantitatively in long trials with large numbers of patients and analysed by means of mathematically-based methods, particularly statistics (Neumann et al., 2007). It is beneficial for patients and for the oncological outpatient unit being studied to determine the effectiveness of therapy. This research is based on a constructivist, qualitative approach which examines the lived experience of patients, their perspectives and their needs and expectations. From the researcher's point of view, quantitative methods cannot provide this personal information.

Cleary and McNeil (1988) stated that many previous studies have had little impact on QOC because these studies are often not designed to facilitate quality improvements and place emphasis on things that have a weak relationship with QOC. However, every cancer patient creates his or her own definition of quality.

This research strategy focuses specifically on the needs of patients with chronic and long-term illnesses because they require continuous, comprehensive care that

is based on their personal needs and expectations. The reviewed literature indicates that most studies that have been conducted to date in this field use quantitative research methods when evaluating healthcare. Most of these quantitative studies and a few qualitative ones report high levels of satisfaction with care and services from patient surveys (Goldzweig et al., 2015). Goldzweig et al. (2015) expressed doubts about the sensitivity of the methods and the ability to differentiate between the complex terms 'satisfied' and 'unsatisfied' because of negative experiences.

As Mays and Pope (2000) pointed out, a range of methods is necessary to understand the multidimensionality of modern health care. Here, qualitative research methods are used to evaluate a patient's subjective experiences. The employment of these methods allows for greater consideration of patient needs, perceptions and impressions of life in general while they undergo medical treatment.

This research firstly examines the current literature based on the identified keywords. Secondly, the case study approach is described as well as the qualitative research design. Data is generated with semi-structured interviews and standardised questionnaires analogous to the SF-12 to evaluate the QOC of oncological patients by gathering their subjective experiences. Thirdly, the researcher determines whether and how quality of life and patient satisfaction define QOC for cancer patients in an outpatient unit. The QOC in the ASC healthcare model is compared with QOC in the non-ASC model. Finally, a conceptual framework is provided: a tool for single healthcare professionals working with a small number of patients which could be utilised to assess their own quality of oncological care. Conducting other studies on this question could provide further sub-categories used as part of an assessment to evaluate the quality of oncological care.

# 1.2 Highlighting a problem

A decisive role in the existing research on the quality of care was played by Donabedian (1980), who demonstrated that quality of care is a multi-dimensional construct that must be researched in order to enhance medical treatment. Aaronson et al. (1993) later developed this train of thought by creating quantitative questionnaires that aimed to evaluate the quality of care. These questionnaires investigated aspects such as the health status, social functioning and psychological wellbeing of patients (Aaronson et al., 1993). Ware et al. (1995) and subsequently, Kleeberg et al. (2005) built upon Aaronson's findings by focussing their questionnaires specifically on patient needs and perceptions. However, their studies were still quantitative rather than qualitative.

To support the diversity of medical research, a qualitative approach will gain a broader understanding, whereas no quantitative research method will be able to describe patients' realities, lives, and minds (Mays & Pope, 2000). This research chose a qualitative approach because of a relatively small number of participants whose meanings would be shaped by their unique circumstances. In such a qualitative approach, particularly useful for applied research, it is not only important to measure outcomes rigorously or to compare results with others, but also to understand the processes for the given situation (Cleary & McNeil, 1988).

Much research has already been conducted that focuses on the multi-dimensional aspects of quality of care (Wild & Patera, 2013; Wilde Larsson, Larsson, Wickman Chantereau, & Staël von Holstein, 2005; Yamagishi et al., 2014; Zapka, Taplin, Solberg, & Manos, 2003). However, no scheme has yet to adequately evaluate quality aspects of care from a patient's point of view by combining self-administered semi-structured interviews qualitatively and standardised questionnaires (analogous to SF-12) in a single outpatient clinic. Standardised questionnaires with well-established quantitative designs are widely used to evaluate quality of life in oncology (Baumann et al., 2008; Bullinger, 2016; Velikova et al., 2008). Researchers concluded that the participation of patients in the process of their treatment is an integral part of quality improvement in health care in the outpatient unit. Patient satisfaction and quality of life are important elements of quality improvement and patient-centred care and are indicators of the public's confidence in the health care system (Koller et al., 2009). These aspects are now becoming research topics.

This relates to the key factors of the PASQOC (patient satisfaction and quality of life in oncological care) study (Kleeberg et al., 2005). The PASQOC study tries to identify the current key factors of PS and QOL in oncological outpatient clinics in Germany as well as socio-demographic and psychometric data. The PASQOC study is a multicentre quantitative study focused on the quality of treatment in specialised medical practices in Germany. However, for outpatient medical clinics, this quantitative approach cannot be used to evaluate the quality of oncological treatment promptly. In addition to this, the small numbers of patients in single medical clinics mean that quantitative approaches are statistically not feasible. Multicentre quantitative surveys are neither prompt nor focused on a single practice.

Therefore, this study adds depth to this approach by using qualitative research that evaluates the quality of care in health care models from the patient's perspective.

The research will make a significant contribution in this field because there is little

detailed knowledge about the qualitative and subjective experience of patients with gastrointestinal cancer diseases undergoing ASC in a single outpatient clinic. The study considers the interdependency between PS and QOL and to what extent other variables influence the quality of oncological treatment. Patients of a single outpatient unit can usually be considered as a heterogeneous diverse group. For these patients, a qualitative approach should be able to estimate the need for intervention for improving their quality of life.

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Thus, while many studies have evaluated quality of care, the majority of these, as mentioned above, have employed quantitative research methods. This research will adopt a qualitative approach. A possible disadvantage to this research approach is that a qualitative case study is limited to a small sample size (in this case, two groups of 10 patients). It is for this reason that the researcher supplements the recorded semi-structured interviews with an analogous standardised questionnaire.

The section of this research that evaluates Germany's new ASC model is important because, currently, minimal research has been conducted on this topic. It is always necessary to pay particular attention to PS and QOL while government regulations are being changed and new healthcare models are being implemented (Coenen, Haucap, & Hottenrott, 2016). It could be that the results of this research will be used in the future to improve the structure of ASC in the oncological outpatient unit being studied, or even in other outpatient units. This research is not intended to develop a new questionnaire or to generalise, but rather to obtain more indepth patient information that could be used to enhance the quality of oncological care. This study will be useful in raising consciousness about the problem of determining how to evaluate quality of care best and will help to assess the new ASC model.

Kleeberg et al. (2005) and Patton (2002) have shown in their studies that good oncological treatment and appropriate quality of care, as well as patients' requirements, are not mutually exclusive. Kleeberg et al. (2005) stated that oncological quality becomes relevant even if a high level of quality exists, but quantitatively no conclusions can be drawn, and no sufficient criteria for comparison exist. It will be helpful to thematise and narrow down the terms of QOL, PS, and QM in the next section.

#### 1.3 Overview – Research Background

The following paragraphs begin with the research background that sets the stage for the research problem and the purpose of the study. The relevance of the topic

will be further explained based on the existing theory and research from the literature. Each of these elements are described in greater detail in the following section.

#### Quality management and the perspective of patients

There are existing traditional methods when evaluating quality assurance in health care. However, these methods do not follow systematic rules and are not coordinated (Schmalenberg, Hartmann, & Baumann, 2010). Donabedian (1980) classification of structure-, process-, and outcome parameters was established to evaluate healthcare services and doctoral medical treatment. Structure refers to medical supply in the sense of staff, institution, room and instrumental requirements and resources. Process refers to qualified personnel whose actions aid operation, therapy and rehabilitation aiming to obtain a high health-related quality of life and satisfaction with the treatment. Requirements of structure- and process parameters are defined by profession and by law. Campbell, Roland, and Buetow (2000) extend these notions with the terms 'efficiency and equity', meaning that every patient has access to and receives the diagnosis and therapy he or she needs.

The development of quality indicators allows the opportunity to integrate measurable and specific items of supply to evaluate the quality (Schmitt, Petzold, Eberlein-Gonska, & Neugebauer, 2013). Quality indicators measure quantitative aspects of care that are relevant to most patients and related to their specific diseases. Non-ambiguous quality indicators can be used for a representative measurement of specialised areas in health care units, as Schmitt et al. (2013) stated, to improve treatment (e.g. performance indicators are relevant for comparison of quality parameters or patient-reported outcomes).

In the UK and US, evidence-based RAND corporation quality indicators are popular. These indicators were developed nearly 40 years ago (1980 in California). The National Primary Care Research and Development Centre (NPCRDC) implemented the so-called RAND/UCLA method in primary and specialist care, which used a combination of evidenced-based indicators from random controlled studies with a structured assessment from experts (Brook & Gompert, 1994).

The Delphi method was developed at the beginning of the cold war and made popular for research by project RAND in 1963 by Olaf Helmer, Norman Dalkey, and Nicholas Rescher (Dalkey & Helmer, 1963). This qualitative survey method provided expertise systematically and relied on a panel of experts. The principle of the Delphi method was to circulate multiple rounds of questionnaires which were anonymously filled out by a panel of experts. The results of the questionnaires

were shared with the group and discussed after each round. This process was repeated until a consensus was reached (Dalkey & Helmer, 1963).

These different methods should show how quality can be measured quantitatively, and results can also be shown in interpretable measurements. A limitation in these cases could be that for gathering quality measurements, the documentation of treatment steps was influenced by the treating doctors and depended on the various documentarists. There are also disadvantages in the reliability of information from other individual patients and exclusion criteria for routine treatment in practice. Also, the patients themselves and their personal experiences are more or less irrelevant.

ASCO's quality oncology practice initiative (QOPI) is an oncology practice-based quality program established in 2006, measuring defined data in cancer care to improve quality. This program aims to promote self-observation in a well-accepted quality management program for ASCO members in registered oncology practices. The defined measurements based on guidelines provide data for comparison among other practices twice a year (Neuss et al., 2005). As Neuss et al. (2005) stated, publications on oncology provide information on outcome and medical treatment within large groups of patients but only offer limited insights to practising oncologists about the quality of their work. The limitation for the QOPI tool in this approach is that doctors can only measure the medical processes they have control over and depend on the cancer-related behaviour of patients. Also, Neuss et al. (2005) stated that QOPI evolved rapidly and the number of practices has increased, allowing a comparison of their quality of care. However, the patient perspective is a core dimension of quality management procedures (Bitzer, Dierks, Dörning, & Schwartz, 1999). According to these researchers, it is particularly important to identify the needs of patients, to fulfil these needs and to enhance satisfaction in the process of continuous improvement.

Regular service and a patient satisfaction survey are often used to record and monitor relevant parameters to evaluate the quality of medical clinics (Bitzer et al., 1999). Zapka et al. (1995) argued that patient experiences in quality assessment can be used to gain insight into individual treatment and can provide feedback about quality. Only patients can achieve this feedback because they are the ones who have passed through the entire treatment process. Furthermore, medical institutions aim to receive concrete suggestions from patients' feedback, particularly about ambulatory outpatient care. In addition to providing information about a patient's background, surveys provide relevant information about PS with the medical treatment. This can only be achieved if we know the main characteristics

of patients' needs and their perspective on their specific treatment in an outpatient clinic in comparison with other activities of internal and external quality management (Schmalenberg et al., 2010). It is necessary to obtain a fuller picture of the care process and to realise what criteria are important for PS in a doctor's practice. This broader overview of PS and quality criteria are included in the literature review in chapter 2, which discusses various qualitative studies with smaller numbers of patients in outpatient clinics. This study based its inquiry on the PASQOC questionnaire developed by Kleeberg et al. (2005) to obtain concise, concrete information about patient perspectives in a user-friendly fashion. The researcher modified this questionnaire by developing her classification system consisting of three main items: interpersonal, medical and organisational features. For further evaluation of structure and process-quality in the doctor's surgery, 31 subcategories were identified, all dealing with various aspects of disease and its treatment.

These defined items of structure-, process-, and outcome quality are organisational, interpersonal and medical items that can have different valuation and importance for the patients. Aspects of process quality are shared-decision-making, autonomy, information and communication, coordination and documentation. For gathering the importance of PS, there follows a numerical approach of the chosen items (see chapter 4, methods). To understand how and why the patient groups were selected for the study, it is vital to understand both the German outpatient medical health care system in general and outpatient medical care in oncology. The following sections address these topics.

#### Outpatient medical care in Germany

Germany's healthcare systems are historically based on residential general outpatient care, specialised care and hospital care (Amelung, 2007). In Germany, everyone has the right to health and nursing care (Micheli et al., 2003). There are four basic principles of supply for all citizens. Firstly, all citizens must have either public or private health insurance. Secondly, all citizens and employers must financially contribute to the healthcare system by way of their tax revenues. Thirdly, a solidarity principle: in health care, all members share a personal risk for payment in case of illness. Each statutory insured member maintains the same rights irrelevant of how high or low their income is. Fourthly, the principle of self-government: regulated by the Joint National Committee, in this autonomous governing body are representatives from practitioners, psychotherapists, dentists, hospitals, insurers and insured persons. Self-government means to fulfil tasks of public interest for the security of care which is otherwise fulfilled by the nation.

The outpatient specialised care and hospital care are supplementary service areas. Doctor-patient-relationship and continuity of support play a unique role in general practice especially for chronically ill patients, as do coordination of care and transparency of information (Bredart et al., 2015; Vân France et al., 2011).

#### Outpatient medical care in the European context

The Sécurité Sociale is the French National Health System and is funded by contributions from citizens and employers. Like Germany's health care system, the French system includes both public and private health facilities (since 1945). Patients are free to choose their treatment regardless of their social or work status. Both the health care systems in Germany and France deliver high-quality service with expenses among the highest in Europe (Micheli et al., 2003).

As in Germany, patients in the United Kingdom have free access to their health care system. In Germany, direct medical supply and treatment are from medical specialists. The National Health Service (NHS) in the UK provides healthcare to any person who requires care. This organisation provides many different forms of healthcare (doctors, pharmacists, and so on) and is primarily funded by taxpayers. Dentistry in the UK is free if patients are under 18 years or 19 years and in education, pregnant or have given birth in the last 12 months, on benefits, or in hospital dentistry. Both Great Britain and Sweden entirely finance their health care systems from tax money (Davidson & Mills, 2005).

General practitioners (GPs) in Sweden and Norway mainly guarantee primary care. Referrals to medical specialists and hospitals take place only in complex and severe situations. GPs manage health care as gatekeepers, offering an area-wide form of care due to the specific situation for cancer patients in these nations (Busse & Hoffmann, 2010).

#### Outpatient-medical cancer care

Aspects of cancer treatment in Germany are carried out in outpatient practices and private clinics, with inpatient care in public hospitals. In 1971, the cancer program was started, and in 1982 free annual tests were implemented to screen the population for rectal, breast, prostate, skin and cervical cancer (Micheli et al., 2003). A milestone in oncology was the so-called oncology contract in 1994 between particular insurers and the association of statutory health insurance physicians to improve oncological care (Kleeberg, 1994). Specific measures were implemented, e.g. the responsible oncological physician, qualified outpatient treatment close to patient homes, and further inclusion of authorised clinicians. In 2009, a nationwide oncological agreement was decided upon for quality improvement for

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engaged and responsible doctors (Schmalenberg et al., 2010). What exactly did this agreement do? The aim was to improve the qualified outpatient treatment of patients with cancer diseases by contracting physicians. Thus, the outpatient oncological treatment ensures an alternative for inpatient care but not for follow-up care of cancer patients. The obligations under this agreement do not apply for other competitors or hospitals.

In the 2000s, the German Cancer Aid (the original cancer treatment program was established in 1971 (Micheli et al., 2003)) and the German Cancer Society provided the concept of three-step care for oncology: Oncological treatment in organ cancer centres (breast, bowel, lung, prostate), association of various organ centres and the institution of comprehensive cancer centres (CCC) all provide a higher-level status of treatment. These cancer centres were established to increase the quality of oncological patient care and contribute to clinical cancer research (Klinkhammer-Schalke, Marschner, & Hofstädter, 2012).

In 2006, a nationwide clinical tumour registry was established to increase the quality of supply and to develop guidelines for treatment recommendations (Hermes-Moll, Dengler, Riese, & Baumann, 2016). The German Competition Re-Enforcement Law, created in 2007, constituted a development of quality assurance in medical health care. This law enforced that the prerequisites for quality in outand inpatient care should be implemented cross-sectorally as much as possible. The goal of this development was to evaluate treatment procedures by service providers and over more extended periods. Improvement of quality and the autonomy of patients should be strengthened. Identical examination in both treatment areas in inpatient and outpatient care and overlapping activities could then avoid over-, under or misuse of resources (Straub & Müller, 2007).

In February 2008, the German Cancer Society and German Cancer Aid created the guideline program in oncology. Guidelines are part of the quality management system and have been introduced to improve processes and outcomes in healthcare in oncology. Patient-centred care was defined through the guidelines of the National Cancer Plan that place great emphasis on quality (Wesselmann, Winter, Ferencz, Seufferlein, & Post, 2014).

In July 2009, the oncology contract was implemented to support the outpatient supply of patients with current cancer diseases in statutory ambulatory care as an alternative to inpatient treatment (Hermes-Moll et al., 2016). Regulated by law, the Federal government requires cooperation between physicians from multiple disciplines for interdisciplinary discussion of treatment options on so-called tumour boards. Internationally, tumour boards are also called multidisciplinary cancer team-meetings. There is no standard structure, organisation, membership or

frequency of these meetings (Hermes-Moll et al., 2016). However, as Hermes-Moll et al. (2016) considered, the patient's perspective is inadequately represented, and feedback is rarely given to patients after their case is presented. Therefore, lawmakers established paragraph §115b in 2000. This meant that hospitals allowed outpatient surgery. In 2004, §116b allowed outpatient treatment in hospitals for patients with rare and severe illnesses. This resulted in competition between hospitals and outpatient specialist practitioners. However, among the states with the German competition reinforcement law in 2007, integrated care has been maintained and essentially self-regulated. Under the new version of § 116b in February 2012, the implementation of the ambulatory specialised care (ASC) promotes the cooperation of medical specialists and approved hospitals for the outpatient diagnostic and therapy of severely ill patients (Meißner & Rieser, 2012).

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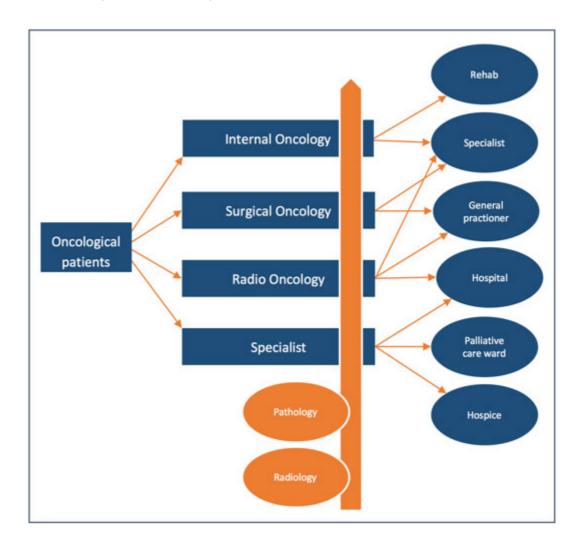
This specific research case investigates diagnostic and treatment options of severely ill patients with gastrointestinal cancer, which need adjuvant or palliative complex tumour treatments. Adjuvant therapy is a treatment that might include an additional operation, chemotherapy or radiation therapy to increase the results of previous treatment or to prevent new occurrences. Sometimes supportive therapy is necessary to reduce or mitigate the side effects of prophylaxis cases or chemotherapy. This can result in better outcomes for the patient and can reduce the time of hospitalisation. From a historical oncological perspective, the term palliative refers to a cancer disease that is not curable (Osse, Vernooij-Dassen, de Vree, Schade, & Grol, 2000). The terms palliative medicine and palliative care refer to all parts of the therapy process and the supportive care provided to mitigate symptoms of the disease and pain (Smith et al., 2012). Palliative care takes into consideration the environment, the family members, and the time at the end of life. The approach is to increase the quality of life. Taking into account the rapidly changing supply needs of a rising number of older people, severely ill and in need of care patients requires an increasing medical supply in their surrounding area either ambulatory or in hospital (Albrecht, Loos, & Otten, 2013).

# The current structure for the treatment of patients with tumours (see Figure 2)

By the law (of the Federal Joint Committee), an increase in quality structure and optimised supply conditions should be achieved with equal access between hospitals, physicians and doctors established. The treatment borders between hospital and ambulatory sectors were historically separated. Outpatient operations in 2010 (§115) and ambulatory treatment in hospital in 2012 (§116b) were implemented by lawmakers to overcome this problem of rigid structures, along with integrated care in 2013. The G-BA (Federal Joint committee) will enhance the new

health care sector through optimisation and improvement for chronic illness patients and conceptions for new supply structures for those with severe oncological diseases.

FIGURE 2: THE CURRENT STRUCTURE FOR THE TREATMENT OF PATIENTS WITH TUMOURS (OWN DRAWING)



#### Outpatient medical cancer care in the European context

Cancer care in France is covered by the national Sécurité Sociale and includes all costs of cancer diagnosis, treatment and surveillance. They provide a structure of comprehensive cancer centres and university hospitals which are scattered all over France. In France, about 50 % of cancer patients are treated in these centres and 50% treated in private medical practises. The private sector covers extensive cancer care with radiotherapy and chemotherapy in all urban areas (Wilde Larsson et al., 2005).

In the UK, cancer patients receive treatment of varying quality. In May 2016, NHS England established a very high standard of cancer care designed with various steps to speed up diagnosis, increase prevention and help patients live with the cancer disease and beyond (Baird et al., 2016). Aims of the system are to ensure that all patients receive access to specialist services and that there are no waiting times longer than 62 days between suspected cancer diagnosis and starting treatment / 31 days starting treatment after agreeing the treatment plan. The national cancer program (Cancer Strategy Implementation Plan) seeks to ensure that cancer patients receive the best treatments, support and care (Baird et al., 2016).

A strategy of this cancer program is to enhance prevention, screening, treatment and all other investments needed to build a strong cancer workforce for the future (Asch, Kerr, Hamilton, Reifel, & McGlynn, 2000). A medical quality indicators system was established to evaluate the quality of care and costs (Micheli et al., 2003). To improve cancer outcomes, The National Cancer Peer Review Program covered all types of cancers. In addition to this, the National Confidential Enquiry into Patient Outcome and Death reported on cancer care towards the end of patients' lives. As Wilde Larsson et al. (2005) pointed out, the quality assurance program has improved the quality of cancer care in the UK through the development of quality indicators in addition to the NHS efforts.

#### Outpatient-medical care in oncology under the ASC

In the ASC system, patients are commonly treated on an outpatient basis by medical specialists and in hospital by physicians. Additionally, the service has been expanded and improved for patients with complex, severe and rare diseases (Klakow-Franck, 2014b).

The development goes back to the law of basic supply, which was implemented with the idea of nationwide support of high-quality diagnostics and therapy for patients with severe diseases. Through the modified law of the health system, the Federal Health Minister implemented the first version of § 116 b for hospitals which caused unfair competition between the outpatient and inpatient specialised care (Gerlach, 2012). In the guidelines from the Joint committee, § 116b was established in 2012 in the Social Insurance Code, Book V. This created an inter-sectoral service area. For the first time, statutory medical specialists and hospital doctors cooperated to treat patients with special indications under the same conditions. Depending on the disease and what specialised doctor is necessary, the interdisciplinary cooperation requires special conditions nationwide that are regulated uniformly (Gerlach, 2012).

Since December 2013, ASC has provided coordinated care of different diseases by a specialised interdisciplinary team formed of multiple medical specialists (Hess, 2013). ASC is not part of the licensed supply. This means that payment is extra. In April 2014, care for tuberculosis was implemented. ASC came to cover gastrointestinal tumours in July 2014 (Coenen et al., 2016). Since then, other diseases have been implemented. They are not the subject of this research.

For patients, participation in ASC is voluntary. Organisational and structural requirements for patients continue close to home in the current environment of the participating practice. The guidelines stipulate comprehensive, in-depth information for patients about the provided service, treatment and additional range of services (Robra, Swart, Thomas, & Vogt, 2010). With the implementation of the ASC, the lawmaker's objective is to overcome sectoral borders with this new supply sector and to increase the quality of care. Basic conditions in the current care provision involve more information about cooperation, coordination and the existing quality of care. These are the expectations from the health care policy to the ASC as Gerlach (2012) derived from his special report in 2012.

As mentioned above, politically created competition in healthcare between office-based physicians and hospitals can lead to a competition for quality. The origins of this research were the absence of adequate measuring values for the quality of outcomes which are caused by the small number of cases in outpatient clinics, for most indications are too low for valid and reliable measurement (Gerlach, 2012). The Federal Joint Committee defined uniformly only the structural quality as a prerequisite for outpatient and inpatient care to guarantee high-quality care, but the aim is the orientation on patient-relevant outcomes concerning continuous quality improvement (Dengler & Cassens, 2018).

#### Ambulatory specialised care (ASC) in the European context

The amendment of the above-mentioned §116b and the subsequent development of ASC in Germany is also important on a European level. In early April 2011, the EU issued a directive to ensure cross-border healthcare for a patient's rights. The directive requires insurance companies to permit cost-intensive and highly-specialised care across borders. Other nations predefined and determined the annual cost of providing therapy.

International literature provides no comparable insights to Germany's ASC system because other nations with broad health care research have no medical specialists in outpatient medical care (Patera, 2011). Germany is in the upper range in terms of high demand for hospital services, high number of outpatient surgeries, and

high amount of patient contact compared with other OECD nations (Wild & Patera, 2013).

In Great Britain, specialised indicators create ambulatory care sensitive conditions (Purdy, Griffin, Salisbury, & Sharp, 2009). One indicator for a negative outcome is frequent inpatient hospitalisation. Weak supply and avoidable death are fortunately rare, but a potential negative outcome is an avoidable hospital admission for diseases which can be treated in outpatient care. As a consequence, poor quality in coordination and cooperation, poor access and deficiencies to health care are indicators of great interest (Coenen et al., 2016).

#### Comparison of the ASC and oncology contract

TABLE 1: Comparison of ASC and oncology contract presents the similarities and differences between the existing oncology contract and the new ASC model. The table outlines the aims and definitions of both models. The participants who did not have access through the oncology contract will profit from the new health care model if participation is possible. However, the advantages of participation for patients and doctors can only be exercised two years after implementation due to the required evaluation. The initial feedback in Bavaria after seven quarters gives an impression of how it looks (Kaiser et al., 2017).

TABLE 1: COMPARISON OF ASC AND ONCOLOGY CONTRACT

Comparison of ASC and Oncology contract			
	ASC version of (26.07.2014)	Oncology contract version of (01.10.2009)	Neither regulated in ASC, nor in Oncology contract
i	Determination of the disease subsection of GI cancer: Diagnosis and therapy of rare, serious and severe (07/2014) or complex courses of disease which are difficult to treat. Highly specialized services. Trans-sectoral health care. Need of special qualification of doctors.	Support of a qualified outpatient treatment of <u>all cancer patients</u> with statutory health insurance.	Active involvement of patients is not provided.
2	Participants are office-based physicians and authorized hospitals.	Alternative to inpatient treatment. This agreement is not for doctors from hospitals according to § 116 b.	Participation in one of the two health care models. Specialized palliative care is excluded.
3	Extended Federal Committee.  To overcome the existing transsectoral health care.  Incentives for more quality and incentives for care providers.	Approval from the physician association.  Existing competitive differences.	Liability questions unexplained. Higher costs on account of separate accounting. Concerns about uncontrolled cost expansion. Do not cover relevant costs of participation.
4	Contractual agreements with seven or more cooperation partners from different areas: surgery, nuclear medicine, ear-nose-throat doctor, nephrologist and other specialists from other disciplines.	Interdisciplinary community with four cooperation partners from pathology, radiology, radiology, radiological oncology.	Difficulties for rural area- wide application caused by barriers of participation requirements.
5	Collaboration of the interdisciplinary team (team leader, core team, and all consulting specialists). Weekly office hours located at the medical practice of the team leader.	Close and lasting association with all participating partners.  24h accessibility.	

6	Medical specialist can only be approximately 30 minutes away from treating location.	Outpatient care located nearby with qualified partners.	Difficulties for rural area- wide application caused by barriers of participation requirements.
7	Inclusion of other professionals e.g. physiotherapist, psycho-oncologist	Not regulated	Distinct differences between: Participation of general practitioners, health-care professionals and relatives of patients.
8	Continuous cooperation with self- help-groups	Not regulated	
9	Conclusion of a cooperation agreement with the participating doctors from hospital and outpatient practice.	Close and lasting cooperation and continuous exchange of experiences with the participating partners (see also point 4)	
10	Joint quality-oriented conferences at least twice a year	Not regulated	
11	Evaluation after at least two years	Not regulated	
12	Information sheet for patients about the participation in ASC. Signature is required.	Not regulated	
13	Not regulated	The general practitioner receives regular information about the treatment in written form	No clear regulation who should get detailed information
14	Not regulated	Not regulated	Aftercare for tumour patients
15	Not regulated	Not regulated	Evaluation of patient- relevant endpoints

# 1.4 Stating the purpose of research

This research pursues two main questions: The first question is whether it is possible to assess the QOC of patients in one single outpatient unit by evaluating QOL and PS. The second question is whether and how patient evaluations of QOL and PS change with the new German model of Ambulatory Specialised Care (ASC). The importance of these questions must be explained in more detail.

Every working oncologist should prove their own quality of oncological care and how beneficial it is for the patients. The quality of oncological care (QOC) consists of so-called "hard endpoints" such as morbidity data, overall survival and response rate; as well as "soft endpoints" such as QOL and PS. Reliable results of hard endpoints can only be collected quantitatively and need large numbers of cases for significance. Qualitative studies have shown that from evaluation of PS and QOL, a conclusion regarding QOC is possible. The results of Kleeberg et al.'s (2005) PASQOC study suggested that QOL and PS are favourably influenced when a good medical outcome is achieved. Therefore, the quantitative PASQOC study was used as a reference for this study.

This research seeks to address whether single outpatient units can determine qualitatively the relationship between PS and QOL based on their small number of cases. To answer the second part of the research question, the researcher compares the qualitatively obtained data of PS and QOL belonging to two groups of patients with and without ASC. The group without ASC is examined under the conditions of the existing oncology contract model. The main objective of the second question is how beneficial the implementation of a new oncological supply model is for patients.

In this research, semi-structured interviews are used to evaluate PS. QOL is evaluated with a standardised questionnaire analogous to the short-form-12 questionnaire (SF-12). These results of PS and QOL consist of physical, psychosocial and emotional well-being aspects, which are compared in two groups of patients with and without treatment under the conditions of ASC. It is not clear whether national law and the regulations of the leading associations for health care are primarily focused on the quality of care or whether they focus instead on political and economic circumstances. Publications on oncology provide information only on the outcome and medical treatment within large groups of patients as a measurement for quality. They offer limited insights to practising oncologists about the quality of their work (Kleeberg, Feyer, Gunther, & Behrens, 2008). According to these researchers, there is a need for key parameters of PS and QOL that are important for practising oncologists to receive information about the quality of their own work.

This research focusses on patients' perspectives and experience as a core dimension of quality management processes to fill this gap as a new approach; the goals of this study are first to qualitatively determine whether PS and QOL can be used to evaluate a patient's QOC in a single outpatient unit and secondly to determine how the QOC under the oncology contract compares to QOC under the ASC model, as perceived by the patients. The acquisition of data about the quality of life and patient satisfaction leads to increased transparency and could lead to higher quality of treatment outcomes and be used to assess structural changes to improve the quality of oncological treatment. The data generation, consisting of both an interview and a questionnaire in a single case study aimed to compare two groups of patients undergoing oncological treatment in a single outpatient unit by way of semi-structured interviews and standardised, not disease-specific, questionnaires (SF-12).

To provide the reader with an understanding of the conditions which brought about the research problem, it is now relevant to report on the background of the study and the researcher's personal interest in the topic. Having worked for more than 20 years in an outpatient oncological medical clinic, the researcher gained knowledge and professional experience that led her to question how good the quality of oncological care was for the patients in her medical practice. This led to the fundamental question of whether the quality of care is beneficial for patients and to understand the patients' behaviour. These meditations also caused the researcher to wonder about internal and external influences on the conditions for a continuous improvement process (CIP). Staff members, nurses and doctors cause internal influences. External influences are caused by the framework established by German lawmakers, changes in the healthcare sector, demographic change, organisational prerequisites, and cultural, and social factors (Glaeske, 1999).

The researcher developed a qualitative study, given the small number of patients in a single medical practice. The strength of the study lies in this fact, considering their individual and unique circumstances. This contrasts with quantitative studies which investigate a large number of participants over a long period in many different medical practices (Feyer, Kleeberg, Steingräber, Günther, & Behrens, 2008). The qualitative approach is positive because it results in different data generation. This means that the "hard" oncological endpoints like progression-free survival, response rate, outcome and overall survival are more quantitative forms of data. This kind of data does not apply to small, individual patient groups with diverse, individual diseases and emotional states. As Kleeberg (1998) stated, the comparability of the outcome is unfeasible when only based on the quantitative quality of life results. The solution to this problem lies in the data generation of the PASQOC

study developed by Kleeberg et al. (2005). The results of the PASQOC study confirmed that most patients are very satisfied with the outpatient oncological care. However, the potential for improvement from a patient's point of view consists of shared-decision-making, communication between doctors, other institutions and patients, information and continuity of support. One key point for PS from the patient's position is to recommend the practice. As (Bartsch, 2004) pointed out, follow-up measures are necessary to determine the influence on PS through detailed quality assurance measurements.

From the researcher's point of view, the results of the PASQOC study best described the oncological quality of care, which addressed the key parameters of patient satisfaction and quality of life. This is important for outpatient oncologists to receive information about the quality of their work.

As mentioned, healthcare research should not be reduced to one specific method or design because of the different size and range of questions, which can be approached by both qualitative and quantitative methods (Glaeske, 2013). A review of relevant literature can provide an overview of the existing theory.

#### 1.4.1 Synopsis of literature

The WHO provided a comprehensive definition of health in 1948: 'Health is the perfect status of physical function, mental status and social well-being' (Grad, 2002). Health-related quality of life (HRQOL) must be viewed in a particular treatment context of physical and social well-being. The theme is much more broadly explained by Schumacher, Klaiberg, and Brähler (2003):

#### TABLE 2: "HEALTH" (SCHUMACHER, KLAIBERG AND BRÄHLER, 2003)

- Illness specific symptoms, patients defined these symptoms as a primary cause of limitations of quality of life.
- Psychological symptoms, in case of emotional situations, well-being and QOL in general.
- · Sickness related functional limitation in daily life.
- Interpersonal and social interactions and illness-related limitations in this special area.

In medical literature, the term quality of life was first established in the 1960s and became increasingly popular in the following years. In 1975, it appeared for the first time in medical databases such as PubMed (Ware, Davies-Avery, & Stewart, 1978). Health-related quality of life (HRQOL) does not only depend on the absence

of illness-related symptoms. It represents a subjectively experienced multi-dimensional construct. Quality in healthcare can be divided into three categories (Donabedian, 1966):

TABLE 3: THREE CATEGORIES OF HEALTHCARE (DONABEDIAN, 1966)

- 1. The technical quality of treatment, treatment that is current and state of the art.
- 2. The quality of personal.
- 3. Interpersonal relationships between staff, team members, and doctors which should be treated with respect, appreciation and trust and the quality of the environment, which should describe the spatial and chronological circumstances.

The definition of quality of care stems from the American Institute of Medicine (IOM). This term is based on current professional knowledge and points out the degree to which health services increase the likelihood of desired medical outcomes (Lohr & Schroeder, 1990).

Lohr and Schroeder (1990) introduced the concept of appropriateness which stems from the Department of Health from the NHS (the NHS is a body of the Department of Health). This concept argues that the quality of medical treatment must be executed correctly. It is important to avoid over-use, under-use and misuse of health services with respect to the patient's wishes. Bullinger (2014) declares that the term quality of life refers to physical, psychological, social and functional aspects of human experience and behaviour. It also applies to cultural differences. Thus, aspects of PS incorporate satisfaction with the treatment concepts and the quality of life in the current living situation. PS and QOL are variable endpoints but very heterogeneous and unlikely to include the different, multifaceted patient points of view. Some patients focus more on factors such as medical outcome, painlessness, and rapid treatment. Others focus on factors such as well-being, that the psychosocial environment is in good order and lesser symptom burdens related to therapy and illness. Both aspects must be considered.

How satisfied is the patient with the process? What does this say about his or her QOL? QOL and PS are relevant parameters because the medical doctor and team strive to meet the demands of good QOC. Medical processes, treatment and symptom burden are expressions of the medical outcome. Andresen and Meyers (2000) stated that it is necessary to study QOL and PS together to gain a more holistic picture of patient experiences, their perspectives and personal needs. However, their studies were still quantitative rather than qualitative.

Using a qualitative approach, Greenhalgh, Abhyankar, McCluskey, Takeuchi, and Velikova (2013) conducted a study that examined oncologists and their patients. The aim was to explore and optimise the patient-related-outcome. This study focused only on patient-doctor-communication. Velikova et al. (2008) also emphasised the value of qualitative research for clinically assessing the quality of life in oncology. Their study focused mainly on medical functions. The appropriate definitions will be expanded upon, and keywords will be explained to fit these different beliefs together and gain a bigger picture of the quality of oncological care.

Outcome measurement is a key indicator for understanding various aspects of oncological care and is usually linked with the endpoints of morbidity, mortality, response and overall survival. Complementary outcome reports have to monitor the toxicity of each treatment protocol and response rates (Velikova et al., 2004). Differences in the overall endpoint results are not only caused by different efficacy of various procedures. Also important are specific groups of patients and their health and social situations (Andresen & Meyers, 2000).

There are many studies of patient satisfaction; however, these studies have different methods, measurements and other variables that make it difficult to compare or evaluate PS of the quality of care (Bredart et al., 2001b). Underlining the complexity of the term, the researcher attempts to define PS scientifically. Donabedian (1988a) defined the structure and processes of care in his quality management model through patient-reported outcome aspects (PRO).

Pascoe (1983) assumed that PS is an emotional reaction to structure, process, and outcome of service and is subjective rather than objective (a structure is aspects of personal, organisational, and technical skills).

Nguyen et al. (2011) compared patient characteristics with dissatisfaction with care as well as specific aspects of patient satisfaction with care in hospitals in his quantitative study. He asked the interesting question of whether improvements in patients' QOL could lead to improved satisfaction with care. A major part of the literature reported more satisfaction from patients who have a strong and long relationship with their physicians (Cleary & McNeil, 1988). It is important to discuss the relationship between influential attributes of PS in this research.

In the following section, the possible influencing factors of this research and the current state of the art are presented. They serve as a basis to derive the research questions and to discuss the results in chapter 6. Besides the influence of PS, this research further examines the determinants of QOL (Küchler & Berend, 2011).

## 1.5 Influencing factors

To reduce the influencing factors, the researcher chose the participants of the study consecutively, based on the inclusion and exclusion criteria which are similar in both groups of patients. The researcher only included patients with the required cancer diagnosis of gastrointestinal tumours. As a member of staff, the researcher has the opportunity throughout the duration of the study to observe the patients during their everyday care. The fact that the researcher and interviewer were also a member of the medical team biased this research; however, relevant steps to reduce any potential bias were made. These limitations are discussed in section 3.7 Ethics and in section 6.1.3 Limitations and opportunities. The researcher followed the University's Ethics Approval Committee requirements and completed a risk assessment form as part of the ethical approval process (see Appendix B Methodology, table 57: Research Ethics approval). The researcher is aware that research with terminally ill patients would not be permitted in the UK; however, it is permitted in Germany.

### Inclusion and exclusion criteria. Recruitment strategy.

- Inclusion criteria are new patients currently undergoing oncological treatment and who have been undergoing oncological treatment for at least two months.
- An expected lifetime of at least six months.
- Over 18 years old, speaks the German language.
- A severe gastrointestinal disease which requires complex oncological treatment.

### Inclusion criteria of ASC.

#### For the group under ASC:

Additionally, these patients agreed to be treated under the conditions of ASC.

All participants who do not fit the inclusion criteria were excluded. All patients were at similar stages of their diseases and had the same inclusion criteria to make them comparable. This research contains an in-depth case-study performed over a definitive period. The focus lies on an analysis of individuals and the experience of individual patients. The conceptual framework of Lis, Rodeghier, Grutsch, and Gupta (2009) suggested a relationship between cancer and fatigue. Adverse conditions, mood and depression, could all influence patients' everyday situations. Klinkhammer-Schalke et al. (2012) stated that comorbidity and progression of the disease influenced the therapy treatment process. In addition to this, Zapka et al. (2003) emphasised the role that health care systems may play in improving the quality of cancer care because financial and available social resources threaten patients. It is necessary to take into consideration aspects from previous studies

to consider other influencing factors. Current research, based on surveys in multiple oncological practices, comprehensive cancer centres (CCC) and the clinical tumour registry, only focus on medical outcomes in multicentre quantitative studies and not on qualitative work in one single outpatient surgery. Routine care of cancer patients differs fundamentally from everyday routine and cannot be seen in randomised controlled trials (Klinkhammer-Schalke et al., 2012). Kleeberg et al. (2005) and Pascoe (1983) did a great deal of quantitative research on QOL. The result of this effort has been the development of code- and keywords.

That a limited point of view is adopted, which only represents a small number of patients, could be an obstacle in this research. The questions arise as to whether the major quantitative points, as shown in the PASCQO study, are more important than other aspects and to what extent these relevant aspects can be answered qualitatively.

The researcher aims to gain knowledge which could potentially be a tool for the future: To what extent can a single outpatient unit estimate and control its quality assurance? The researcher also aims to concisely and effectively answer the research questions. To better answer them, the researcher combined two methods with data triangulation. The semi-structured interviews provide data generation on a broad range of topics. Patient burdens and stress are included in this. Remarkably, PS is only a part of the quality of oncological care and the individual well-being of patients. The combination of QOL and PS builds a broader picture of the entire quality of oncological care and can be treatment dependent or independent. Notwithstanding, there is no doubt about the importance of hard oncological endpoints, as mentioned before.

The interviews were classified into three categories and 31 subcategories to analyse the data. The interview answers with high relevance were allocated to the appropriate nodes (the term is explained in the methods chapter). The categorising approach was self-developed by the researcher and based on keywords from the PASQOC study. The analysis was based on the valuation of nodes and interview questions. These valuations helped to see relationships, e.g. questions in relation to the topics and interview answers, questions for the nodes and questions in relation to each group of patients. Also, all interviews covered broad aspects of quality of supply and quality of care.

The researcher's subjectivity seems to be a potential validity threat. This limitation could be rectified by more research in a larger number of single medical practices, which could lead to more comparability.

### 1.5.1 Synopsis of the research design, methods, sources of data

A qualitative inductive study was the most promising approach for this research. The researcher emphasised individual patient experiences, feelings and perceptions. The focus of this research lay in making observations about the participants and environments involved in the study and using these observations to come to conclusions about the quality of oncological care and the new ASC health care model.

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Before selecting or developing instruments to assess the quality of care, it is useful to have a comprehensive conceptual framework that specifies and defines all relevant domains that are appropriate for describing and evaluating the oncological quality of care and how it affects patient satisfaction and their quality of life. However, for quality of life and patient satisfaction domains to serve as quality of care indicators, the domains must be able to be improved with optimal care.

An important goal is to distinguish quality of care indicators such as structure-, process-, and outcome parameters based on the principles of Donabedian (1980) and derived from indicators of quality of life and patient satisfaction.

The proposed research methods were conducted in 2016 using a semi-structured interview based on the literature review and pre-tested through a pilot qualitative study. The assessment of QOL was based on a standardised questionnaire (SF-12) that was qualitatively validated by the researcher. The generated data was corroborated through methodological triangulation (see chapter 3 methodology).

The semi-structured interviews and standardised questionnaires were conducted with two separate groups of patients. These patients had been given gastrointestinal cancer diagnoses and, at the time of their interviews, were undergoing treatment in the same outpatient clinic. Following the suggestion of Kvale and Brinkmann (2009), who stated that studies should have a minimum number of participants, the two groups consisted of 10 patients each. The first group of patients received care under Germany's current healthcare model. The second group was interviewed four months later and received care under the new ASC model. Both groups of patients were asked to complete the same questionnaires and interviews and were assessed using the same methods. This demonstrates how ASC and the pre-existing healthcare model compare in terms of quality of patient care. The inductive research strategy focuses on structure-, process-, and outcome parameters and on people and environments involved in the study. These observations result in conclusions about the quality of care and the new ASC model. Inductive strategies emphasise descriptions (Denzin & Lincoln, 2009), which is important because this research depends on interpreting patient descriptions of the

quality of care. Through a comparative case study approach, the researcher describes, compares and contrasts social processes and interactions between members of the health care system and patients through data triangulation (Hussein, 2015). Therefore, the standardised questionnaire was not validated statistically but categorised like the semi-structured interview-based protocols.

The object of this case study is a single outpatient unit. With the use of semi-structured interview techniques and standardised questionnaires, qualitative information about patient care can be obtained. As Kvale and Brinkmann (2009) pointed out, the semi-structured, non-standardised, qualitative interview is a multi-dimensional tool that reflects the personal priorities of participants. This is important; the success of this research depends on understanding the feelings, perceptions and expectations of the study participants. Saunders et al. (2011) have suggested that semi-structured interviews can be used flexibly, with the interviewer following topical trajectories and developing additional questions when appropriate. The interviews in the study gathered rich and extensive information about the participants, who could speak freely about their behaviours and beliefs. The interviews were one-to-one and conducted on a face-to-face basis. They lasted a maximum of 30 minutes each and were recorded and transcribed. During the interviews, the researcher took notes about the patient's behaviour.

The interviews evaluated patient satisfaction and the questionnaires evaluated quality of life. The interviews were based on Kleeberg et al.'s (2005) PASQOC study. However, unlike Kleeberg et al.'s (2005) study, these interviews focused explicitly on patient perceptions of satisfaction. From the researcher's point of view, it is both desirable and necessary to ask patients directly about the impact of disease and treatment on their daily lives. The interviews assessed the subjective experiences of patients to provide important insights into the impact of their diseases on daily living. The interviews specifically address the topics of a) health and well-being, b) daily functionality, c) relationship, family and social environment, d) meaningful life, e) financial aspects of support and needs.

Patients filled out the questionnaire two weeks after they had conducted their interviews. The questionnaire was based on the standardised short-form-12 questionnaire (SF-12) (Ware et al., 1995). It is important to note that this questionnaire is generic rather than disease-specific because research on the social factors of health relies heavily on perceived patient quality of life and not on the disease-specific medical conditions (Erhart, Wille, & Ravens-Sieberer, 2006). This questionnaire could reveal the limitations of the healthcare system and could provide insight into how to improve the quality of oncological care.

The idea behind combining interviews with questionnaires in a qualitative assessment is that questionnaires alone are not individualised enough to provide indepth information about patient perceptions, experiences and expectations (Velikova et al., 2008). Questionnaires are also not the best way to identify the supply needs of a specific group of patients (Mallinson, 2002). By combining the more generalised questionnaires with individualised personal interviews, the researcher expected to gain a deep understanding of patient perceptions of quality of care. It is important that the interviews took place before the questionnaires were filled out. This prevented interviewees from being overly influenced by the topics addressed in the questionnaire. The questionnaires and interviews were not based on one another but took a similar approach to Donabedian's (1988a) quality management aspects. The two data-generating mediums made independent findings that, when combined, helped to form conclusions about the overall status of quality of patient care.

Once data were obtained, interviews and questionnaires were coded, re-read and examined (Maxwell, 2012; Saldaña, 2015). The results of the interviews and questionnaires were analysed with the help of computer-assisted analysis software called NVIVO (Saldaña, 2015). The coded data from individual statements were assessed and grouped into broader categories, the so-called nodes, and thematic blocks: interpersonal, medical and organisational. The recorded, transcribed and finally paraphrased interviews were analysed using qualitative interpretative content analysis methods (Mayring, 2010). These content analysis positions are discussed in the methods chapter. This analysis involved comparing the two groups of patients. Each patient's statement was examined individually to identify similarities and differences between the two groups. All irregularities discovered were critically examined and discussed.

The critical examination of the interview and questionnaire results helped with assessing the quality of oncological care in the particular outpatient unit being studied. The study also highlighted the domains in which patients feel that they are experiencing deterioration or lack of support – both in the current health system and under ASC. This information could be helpful in the context of managing and structuring other outpatient units.

The results of this research are not intended to be generalisable; however, some of the themes that are discussed might be applicable in other contexts. The following section indicates who will benefit from this study and how the study results might be employed in the future. Specific groups of patients and their health and social situations are important (Andresen & Meyers, 2000).

# 1.6 Indicating significance, limitations and delimitations

Much research (see above and in the literature review) has already been conducted that focuses on the multi-dimensional aspects of quality of care. However, no one scheme has adequately evaluated quality aspects of care from a cancer patient's point of view by combining self-administered semi-structured interviews and standardised questionnaires (analogous to SF-12) in a qualitative approach. Questionnaires with well-established quantitative designs are widely used to evaluate the quality of life in oncology (Baumann et al., 2008). All the obtained information can be used to facilitate the detection of physical, mental or organisational problems and to monitor the disease of the individual patient's quality of life to highlight the significance of the research. Previous quantitative studies in oncology provide useful information for doctors and team members about QOL but have minor importance for patients' well-being and satisfaction (Huebner et al., 2014; Mays & Pope, 2000).

The inductive, qualitative approach of this research may have some limitations, including the following: The approach is interpretative and subjective and depends on the researcher's personal choices and points of view. Another limitation is the small number of participants. Also, the transferability of the results is problematic given the heterogeneity of patients, the inclusion and exclusion criteria of the chosen patients of the study, and the individual patient's behaviour regarding routine based oncological practice.

## Conclusion

In summary, this research aims to qualitatively evaluate the quality of oncological care in a single outpatient unit by assessing the aspects of PS and the QOL of seriously ill patients with gastrointestinal cancer. Both aspects of PS and QOL are based on the structure-, process-, and outcome quality concept from (Donabedian, 1988b). There are many quantitative studies in this area, yet few qualitative studies. This research adopts a qualitative research design in a single medical unit by looking at the results of the PASQOC study (Kleeberg et al., 2005). By combining the semi-structured interview to evaluate PS with a standardised questionnaire (analogous to SF-12) to evaluate QOL, this research should provide a deep understanding of patient perceptions of QOC. In the following chapter, a systematic literature review will provide the most influential authors that have written about this topic.

## 2. Literature Review

### 2.1 Introduction

This literature review provides an overview of the ideas, theories and significant literature currently available on the topic. It explains what kinds of data are collected in the study and the methods used to obtain that data. As (Hart, 1998) pointed out, a literature review is an objective and critical appraisal of the available literature. A significant issue that this chapter seeks to address is that the definitions of key terms such as quality, QOL and PS are described vaguely and used interchangeably in the existing literature. Part of this is because such terms can be subjectively dependant on the points of view of researchers or study subjects. It is also the case that terms such as PS and QOL are wide-ranging, and are employed in many different contexts in society, marketing and health care (Donabedian, 1980). Key aspects of all research are quality criteria, e.g. validity and reliability. One feature of this qualitative research is that much time is devoted to discussing quality criteria and credibility of processes (Brink, 1993).

This literature review only focuses on the quality aspects of PS and QOL in health care and medicine. There are a rising number of studies which examine quality aspects in general, as (Brinkmann, Steffen, & Pfaff, 2007) have pointed out. Brinkmann et al. (2007) developed a qualitative questionnaire that aimed to collect data on a practical, day-to-day basis about quality dimensions. The idea was that this questionnaire, the "Kölner Patient Questionnaire" (KPF), could be implemented to evaluate quality management systems in outpatient settings. The KPF, while very relevant for researchers performing qualitative studies in outpatient clinics, had its weaknesses. Firstly, the questionnaire did not contain any specific questions for oncological patients. Secondly, many patients, who were severely ill, could barely complete the extended version of this questionnaire because of restrictions imposed by their illnesses. Thirdly, some nurses as members of the team were unskilled and could barely perform the test, which resulted in a reduced rate of return (of 41 practices participating in the study, only 19 responded). Another weakness of this study relates to the importance of questioning patients before they leave the medical practice. For practical reasons, this was not performed in Brinkmann et al. (2007)'s study. The most exciting part of this study was that the questionnaire could be used both in in- and outpatient contexts. Researchers and medical practitioners can use such questionnaires to evaluate the strengths and weaknesses of different care providers.

The researcher of this thesis considers it important to additionally examine individual quality indicators that correspond to the needs of each outpatient unit. This aspect is reflected in the chapters to follow and is a topic that should be further researched in the future.

In this research, the choice between qualitative and quantitative methods is based on the research design and the two different paradigms of positivism and interpretivism. Halfpenny (1997) argues that the choice of paradigm prescribes the method adopted by a researcher. Positivists use quantitative methods and work with numerical and mathematical data; interpretivism uses qualitative methods with the aim of understanding and interpreting the recorded data. This literature review considers the theoretical perspective which underlies these epistemological and ontological backgrounds of the research.

As seen from a social and political perspective, the impact of quality assurance and quality management on healthcare is increasing. Lawmakers and social legislation regulate quality management in medicine. An increasingly important topic is the limited amount of financial and human resources in existing health care systems. In the future, patients will have to take on greater economic responsibilities (Bowling et al., 2012).

Bowling et al. (2012) concentrated their study on measuring patients' expectations of health care through a self-developed questionnaire. Bowling recommends employing better-trained staff and nurses in the health care sector and also suggests that communication should be improved so that patients are better informed about the health care process. She recommends studying the expectations of patients from other areas in oncology or a comparison of questionnaire and interview as a long-term follow-up in longitudinal studies. These aspects are of relevance for this thesis. Rather than focusing uniquely on patient expectations, the researcher of this study compares five key topics: QOL, PS, QM, QOC and ASC.

A starting point for this chapter is the review of the existing literature about quality terms in general. In chapter A of the Appendix, the key authors are sorted thematically according to the topics that they write about, e.g. quality of life, patient satisfaction, quality of care. After highlighting the most important studies, this review critically examines how existing literature relates to the research topic at hand. In a second section, the definition of quality is examined in the context of health care from organisational, interpersonal and medical points of view. These three quality categories are important for understanding the so-called nodes or categories discussed in the methodology, discussion and conclusion chapters. The literature review is organised into five sections, each of which is based on one of five key

search terms. The limits and boundaries of the inclusion and exclusion criteria are examined in detail. Information is presented pertaining to the validity, reliability and robustness of the textual sources and their research findings.

## 2.2 Perspectives of the literature

According to Flick (2014), a literature review helps the researcher to recognise what is already known about a particular subject and what needs to be done in future research. It is pertinent to discuss how the general term 'quality' is employed within the health care system.

### 2.2.1 Literature related to the topic

In the field of health care, many research projects have already been conducted that focus on the topics of QOL, PS and QOC (Bredart et al., 2015; Bullinger, 2014; Kleeberg et al., 2005). The following keywords were compiled for the search terms for this literature review: quality of life, patient satisfaction, oncological quality of care, single outpatient unit, ambulatory specialised care, and quality management aspects in health care. The sources reviewed in this study were narrowed down to those that met the following criteria:

- Primary sources and "masterpieces" with focus on more than 3- 4 of the selected keywords and 13-30 references (a reference to a term).
- Studies that reported significant results and highlighted more than 31-60 references.
- Specialised articles and journals with more than 61-80 references.
- Older, specialised articles with 81-100 references.
- Studies written in English or German and conducted between 2000 and 2018.

This literature review is based on both new and old research. Each topic covered presents first the findings of older, foundational researchers and then delves into a discussion of more recent studies. This structure was chosen to demonstrate the progressive way in which the approach to evaluating multi-dimensional concepts such as QOL, QOC and PS has changed over time. By illustrating the many ways in which the evaluation of health care has developed over the years, this literature review introduces the reader to a thought progression that ultimately led to the creation of the ASC model.

At first, a seminal piece of work to be examined in this literature review is Kleeberg et al. s (2005) PASQOC study. Kleeberg and colleagues used aspects of QOL, PS and QOC to evaluate how cancer patients assess the care they receive and to what

extent patient needs are met. The PASQOC study was performed as multicentre and quantitative research. The specially developed PASQOC questionnaire was paired with the generic SF-36 questionnaire and given to 3384 cancer patients in 24 doctor offices nationwide. Kleeberg et al. (2005) worked with trained nurses who carried out the majority of the studies, following Bowling's recommendations, as mentioned earlier. Kleeberg et al. (2005) determined that there are overall very high rates of PS in the outpatient setting. That said, there are ways in which the PASQOC study could be improved, which the researcher explains in the following sentences. Of particular importance for the current study was the key indicator of patient satisfaction and the willingness to recommend the institution based on a good doctor-patient relationship. Another result of the study was that patients expressed that they did not get enough information about the treatment process and were not able to play an active participating role in implementing their wishes. This negative response showed there was a lack of information for patients whereby the patients' wishes perhaps could be more personally delivered. The researcher of this thesis focuses on these points in her interview questions and questionnaire. Section 2.3 examines the research of Kleeberg et al. (2005) in greater detail.

Another piece of literature that is significant for this thesis is Donabedian's quality management model. Donabedian (1988b) argued that the terms quality and QOC could be divided into three key categories: structure, process and outcome. This three-part approach can be seen as a quality assessment model; a good structure increases the likelihood of good process, and good process increases the likelihood of a good outcome. Donabedian's approach measures quality, QOL and PS with the aim of better understanding the doctor-patient-relationship (see section 2.4.4 The term quality management in oncology). Donabedian's threefold-approach is fundamental to the structure of this research.

#### 2.2.2 Overview of the existing literature

This section sought to place the subject matter of this thesis within the context of existing literature in the healthcare field. Each of the research topics examined in this thesis is viewed in the context of the research that preceded it.

The following paragraphs identify relevant terms and definitions. A table has also been created that provides an overview of the articles that were reviewed, analysed and synthesised (see Appendix A: literature review).

# 2.3 Search strategy and databases

The search strategy for this literature review primarily depended on finding specific search terms, author names and relevant arguments that recurred in internet searches, journals, books and reviews. Mostly primary sources were used.

Five keywords were selected that were deemed to be the most relevant to the topic: QOL, PS, QOC, ASC and quality management aspects in health care. These terms were identified through books and articles that were loosely linked to the subject. The choice of these terms was important because it allowed the pertinent literature to be refined and specified. Research in generic bibliographic-specific databases like Medline (via PubMed), Embase (via Ovid), CINHAL (via EBSCO Host), PsycINFO (via Ovid), <a href="www.webofknowledge.com">www.webofknowledge.com</a> and <a href="www.scholar.google.com">www.scholar.google.com</a> covered most of the topic themes. Kleeberg et al. (2005) discussed most of the keywords in their PASQOC study, which features prominently in this research.

TABLE 4: KEYWORDS FROM PASQOC STUDY (KLEEBERG, TEWS, RUPRECHT, ET AL., 2005)

1 QOL: quality of life and qualitative semi-structured interview of cancer patients

2. PS: patient satisfaction and qualitative semi-structured interview of cancer patients

QOC: oncological quality of care in cancer patients

QM: quality management aspects in single outpatient unit

ASC: ambulatory specialized care

The researcher employed two search strategies: the identification of keywords and the use of the so-called snowball and hand-search method (Greenhalgh & Peacock, 2005). The search was concentrated on recent studies published in the last 17 years, from 2000 until 2017. Only texts written in German and in English were selected.

An electronic and manual search for key terms related to oncology and cancer outpatients was conducted in this literature review. Terms that might also generate papers on QOL, health-related QOL, patient-reported outcome, QOL in oncology and QOL with gastrointestinal cancer were selected. The early 1980s were researched because the term health-related-quality of life (HRQOL) emerged around this time. Specific terms such as HRQL were employed before the year 2000. Some older sources that dealt with topics like HRQOL were therefore consulted although they were published earlier than 2000. Earlier articles were only consulted for background information, however, and were not active parts of the research itself.

In a second step, results were screened for duplicated articles. Articles where no abstract or full text was available were excluded. The remaining articles were selected according to their relevance. The literature was examined to ensure that the in- and exclusion criteria were fulfilled. Original articles which contained the relevant keywords, measurements and instruments used to determine quality for cancer patients were included. A summary of the reference list is attached in chapter 9 Appendix A: Literature Review.

For each study, a table was created with author names, publication year, study/ name, type of cancer and instruments used to collect the data of the five keywords. The main findings and conclusions were rated if the quality criteria were met.

The researcher considered the fact that alternative keywords could provide further information. Broader search terms were therefore also employed, e.g. oncology, truncations such as QOL instead of quality of life and the Boolean operators AND, OR, NOT. A total of 1494 studies were identified.

For the management of references and articles, an Excel spreadsheet was used. Endnote was used as a bibliographic system. Relevant articles were recorded and stored in Endnote. A total of 670 publications were consulted. In FIGURE 3, the search strategy, records, full-text articles and included studies are reviewed.

Search strategy: Quality of life in oncology Search #1 Patient satisfaction in oncology Search #2: Quality of care in oncology Quality management in oncology Ambulatory specialized care Records screened N= 1494 Full-text article assessed for eligibility Included through reference screening N= 824 N= 670 Full-text included for further analysis N= 612 Studies included in review N= 422

FIGURE 3: SEARCH STRATEGY AND SELECTION PROCEDURE (OWN DRAWING)

## 2.4 Towards defining the terms

The main body of this review presents and discusses the findings from the literature. In the following chapter, an initial scope of the available literature retrieved 670 abstracts. While updating the literature review, 612 articles were added. A final total of 607 articles were selected, of which 304 were relevant to the literature review, 54 were relevant to the methodological chapter, and 64 were relevant to the method chapter. In sum, 422 articles were relevant to the investigated topics.

The literature was sorted into three categories (see Appendix: A2, TABLE 42: Defining the terms (own source))

## 1. Background articles

This category included articles about previous research that had been done on the topic at hand. History is relevant when considering a research problem.

#### 2. Empirical articles

This group included articles pertaining to determinants or outcome targets, treatments and settings. These articles discussed specific keyword definitions and described different research methods such as the semi-structured interviews and standardised questionnaires used in this research.

### 3. Instrument related articles

This group of articles reported on methods, research designs and instruments used in data generation in the healthcare setting.

### 2.4.1 The term quality of life

Before delving into specifics, it is necessary for any researcher studying QOL in healthcare to first ask: "what is quality of life and what is a good quality of life"? Once this question has been answered, a researcher can focus on QOL in the context of illness and health. This literature review provides an overview of existing literature on QOL in oncology and reports on findings from studies that have linked QOL with QOC. It is important to note that there are many different aspects of QOL. These different dimensions will be explored in the following paragraphs.

Frommer (1998) discusses in his study of quality management aspects during medical treatments which research methods must be considered to evaluate treatment success. Frommer (1998) developed a framework of quality criteria that should be considered in both qualitative and quantitative methods. These quality criteria were consulted in the development of the qualitative research approach of this thesis.

As Frommer (1998) points out, the previous decade had been characterised by primarily quantitative and statistical studies. Since then, science has striven to answer this qualitative/quantitative question from several philosophical points of view. In the 1990s, a widely-accepted definition was developed which suggested that quality of life is an individual term comprising several constructs. These constructs include happiness, satisfaction and well-being (Herschbach, 2002). The term 'happiness' is a mental state which is both spontaneous and temporary. Happiness depends on the idea that it is impossible to influence one's destiny.

Herschbach (2002) dedicated his time to examining paradoxes, e.g. illness versus health, rich versus poor, objective versus subjective conditions. Interestingly, the constructs of objective adverse living conditions only influenced to a low extent. One would expect that individuals with severe, life-threatening diseases would feel generally negative and that this would strongly influence their emotions.

Sprangers and Schwartz (1999) and Daig and Lehmann (2007) studied the seemingly paradoxical fact that patients with severe chronic diseases report better QOL than comparably healthy people. This phenomenon, known as the well-being paradox often discussed in social psychology, puts forward that severe living conditions do not necessarily affect subjective well-being. Wulff (2007) pointed out that objective disease-related parameters influence a patient's QOL differently than expected. Interestingly, Carr and Higginson (2001) posited that health-related QOL could be understood as a comparison of experiences and expectations. During the illness process, patient expectations change. One must understand a patient's current expectations to be able to evaluate their QOL and PS at any given point in time.

Whether or not this assumption is correct is one of the key questions which the researcher of this thesis has tried to find an answer to. The researcher has also tried to understand whether the results are transferable and whether personal experiences matter or could have potential impact on the future.

Allardt (1973) defined several QOL concepts in different fields of science. The "good life" from philosophy defines the values of life. In sociology, this term refers to the needs and wants of human beings. In economics, the main focus of QOL depends on the resources devoted to fulfilling physiological and safety needs (Allardt, 1973). The researcher discusses the idea of values later in the methods chapter.

In science and medicine, mental well-being and medical interventions are the objectives of QOL studies (Glatzer, 1984). A one-sided, objective perspective cannot provide a comprehensive view of the individual complexities that affect the QOL of patients suffering from individual, severe diseases. Glatzer (1984) points out the relationship between QOL and well-being and the connection of subjective and objective parts. Glatzer states that looking only at objective indicators will cause a researcher to have few inputs and therefore have a limited understanding of QOL. Subjective indicators such as satisfaction are good quality indicators for meeting QOL. The term 'satisfaction', alongside happiness, is also an indication of objective living conditions and quality of life. Each person assesses satisfaction on an individual basis. Satisfaction changes over time because of variation in setting, living conditions and subject areas during one's life (see. TABLE 5: The well-being paradox (own drawing according to Glatzer 1984). Glatzer (1984) defined quality of life as good living conditions and positive, subjective well-being. The term subjective refers to a person's personal views, which are experienced both in general and in special living conditions (e.g. fear, luck, isolation, burden, competences). In contrast, objective living conditions are defined as observable behaviour (e.g. earnings, housing conditions, work- and family relationship). The term 'well-being' is a subjective factor of quality of life and is influenced by personal emotions and one's life history.

TABLE 5: THE WELL-BEING PARADOX (OWN DRAWING ACCORDING TO GLATZER 1984)

Welfare position		Subjective welfare: expectations	
		Good: satisfaction, happiness, luck	Poor: Fear, isolation, burden
Objective living conditions: Family, work, earnings, education	Good	Well-being: Influenced by personal emotions and one's own history	<u>Dissonance</u>
	Poor	Adaptation	Deprivation

Velikova et al. (2004) stated that health-related quality of life (HRQOL) assessments like the cancer-specific EORTC questionnaire have better HRQOL scores; patients also have better emotional functioning outcomes. Therefore, subjective emotional well-being is subject to stronger fluctuation than satisfaction (Velikova et al., 2004). This approach is valuable because when providing everyday care, oncologists factor not only physical but also psychological well-being into their decision making. Good communication between patient and doctor and the need for good QOC are central aspects of quality for cancer patients. This is one of the results of the Kleeberg et al. (2005) study and is an idea that is frequently discussed in the pages of this thesis.

Sitzia and Wood (1998) argued that there are three different aspects of QOL (happiness, satisfaction and well-being) to consider when it comes to caring: treatment details, practical results and patient satisfaction. The study focused primarily on the nursing care being provided to patients, but also included the experiences of cancer patients who were undergoing chemotherapy. Interestingly, Sitzia and Wood (1998) did not see the satisfaction rate of patients as being important for the medical practice but instead identified patient dissatisfaction and the non-cooperation as being of particular value to the research process.

The terms happiness, satisfaction and well-being are components of QOL and relate to three aspects: philosophy – that a person lives a good life; sociology - the well-being of a person; and medicine - health-related aspects. These three aspects constitute the underlying constructs of this research and must be understood by researchers intending to ask questions about subjective and objective patient

experience, attitudes and behaviour (Sitzia and Wood (1998). The researcher adopts this approach and classified the individual interview survey into interpersonal, medical and organisational classification areas. More specifically, QOL incorporates these factors the researcher mentioned above.

- 1. QOL is a multidimensional construct influenced by both subjective and objective components. It primarily reflects the living conditions that patients experience.
- 2. QOL is experienced when patients' expectations are met and is based on their individual needs, wants and choices.
- 3. QOL is influenced by personal attitudes and environmental factors such as relationships, work, education, the standard of living, family life. The meaning of personal attitudes is defined by Patton (2002) as psychological, physical-, social and interpersonal well-being.
- 4. The World Health Organisation defines QOL as an individual perception of living conditions in a cultural context and a perception of one's value systems about aims, expectations, ethics and interests. QOL is dependent on a person's physical health, psychological state and social and environmental relationship (WHO Organisation, 1946).

The term QOL is inconsistently used in the research field. QOL is a multidimensional construct that is highly dependent on personal subjective appraisal (Küchler & Berend, 2011). Küchler and Berend (2011) attempted to measure the effects of treatment interventions regarding QOL in oncology. The EORTC study group in 1975 developed an international validated questionnaire measuring pain and emesis as a broader index towards QOL conditions for patients undergoing therapy. The EORTC was followed in 1980 by the Karnofski Index, which comprehends the medical performance of the observed patients in one measurement. A failing of the Karnofski Index was that it could not account for the complex, multidimensional nature of QOL. The Index gave rise to Ware and Sherbourne's (1992) shortform- SF-36 questionnaire as well as Cella and Tulsky's (1993) Functional Assessment of Cancer Therapy - FACT questionnaire. In oncology, it is understood that QOL for the ill is fundamentally different from that of healthy people. In addition to this, as Küchler and Berend (2011) point out, the value of QOL is highly individual. According to the satisfaction ratio and Herschbach (2002), QOL could be reduced even when a patient is not experiencing essential illness symptoms on account of treatment side effects. In this thesis, the researcher seeks to recognise the complexity of QOL and consider not only physical dimensions associated with the severe illnesses of the patients but also social and psychological dimensions. It is important to understand a great deal about patient well-being to allow patients to make better choices about their plans for treatment.

In the medical field, researchers often focus specifically on HRQOL. This term encompasses the physical, psychological, social, mental and functional aspects of a patient's current health condition, and is, therefore, an exceedingly individual construct (Aaronson, 1988). Aaronson is one of the first authors who worked with QOL assessments in clinical trials in health care. Aaronson (1988) asked patients directly about the impacts of disease and treatment on their daily lives. For this research, the concept of patient feedback is of high relevance. However, unlike Aaronson (1988), this research does not adopt the point of view that the patient's thoughts and emotions can be identified by having patients answer one single question. The approach adopted in this research is one that includes both interviews and questionnaires so that the researcher can obtain the broadest possible amount of information. One disadvantage of interviews could be the lack of resources and the validation criteria; for questionnaires, some patients need help to complete them. An alternative offer is a diary which the patient completes retrospectively, but there could be an issue of compliance with daily entries.

Newer sources like Radoschewski (2000) suggest that patient health conditions do not solely define QOL. Nguyen Thi, Briancon, Empereur, and Guillemin (2002) state that poor health is but one factor that can limit or impact QOL. Moreover, Bullinger (2014) points out that an increasing number of authors are writing about QOL in medicine. As a result of the attention, quality itself has increased. While researchers and medical professionals play a central role in the improvement of QOL, it is also important that patients be informed enough to play a part in the decision making themselves. Working on improving and understanding QOL is a way of optimising QOC. It is difficult to pinpoint the exact difference between health-related and general QOL. Bullinger (2000) proposes that health-related QOL applies to persons who suffer from health restrictions or chronic diseases. This implies, though, that healthy persons do not experience health-related deterioration in their QOL. This assumption is incorrect, as is demonstrated by the definition of health in the preamble of the World Health Organisation (WHO)'s constitution: "Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (World Health Organization, 1955).

Calman (1987), one of the first researchers to evaluate quality of life, suggests that there is a difference between health-related QOL and QOL in general. It is not the case that all patients suffering from illnesses have poor QOL. Researchers should, therefore, understand that it is important to differentiate between QOL dimensions that are influenced by diseases and their treatments and those that are not associated with illness. Newer sources such as Miaskowski et al. (2006) point out that QOL is a broad category. Subgroups of patients who are ill and suffer from severe symptoms are underrepresented in many current studies examining QOL.

In recent years, the investigation of QOL in medicine has achieved increasingly important results. Specifically, in oncology, however, there is still much to be done in terms of gathering and documenting QOL data to implement new therapy concepts (Kleeberg et al., 2005). The implementation of QOL tools as a standardised measurement would allow oncology clinics to obtain complete patient documentation and would result in superior intensive care for patients (Koller et al., 2009).

This idea is upheld by Pakhale et al. (2011), who suggest that evaluating subjective QOL factors in patients is a critical element in tumour therapy. Koller and Lorenz (2003) describe in their health supply research that therapy efficiency has as of yet only been evaluated by criteria like symptoms and extension of life. No patients are involved or asked about their illness experiences. Consequently, there is now a need for self-reported information about individual and subjective patient experiences in research about QOL. As these authors and Schäfers (2008) point out, the model of subjective patient experiences is important, because people tend to adapt to new situations. It is very relevant to see how well-being levels change when individuals are cast into new living conditions. Resources like support from family members and stable social relationships play a significant role in a patient's well-being. The quality dimension models of Glatzer (1984) and Cummins (1996) support this argument and state that there is a need for subjective and objective indicators to evaluate QOL. This requires a qualitative approach performed with precisely those subjective indicators. A substantial part of this thesis is based on patients' self-reported evaluations of QOL and PS.

In summary, it can be concluded that QOL is regarded in the literature as an indicator of QOC for cancer patients. Key factors were recognised that help identify patient perspectives and the degree of PS with care (Kleeberg et al., 2005). Many aspects of care also influence PS. The following section discusses the determinants of patient dis-/-satisfaction as well as the doctor-patient-relationship and QOC.

#### 2.4.2 The term patient satisfaction

Firstly, it is necessary to clearly define the term to understand the scientific meaning of "patient satisfaction" properly. Crow et al. (2002) suggest that satisfaction, in general, is the adequate fulfilment of a person's needs and expectations. Crow and colleagues also outline determinants of satisfaction, e.g. expectations, health status, social and demographic factors. Additionally, they point to the overlapping of patient-doctor relationships and organisational and treatment deliveries of care. Crow highlights the lack of studies focusing on the expectations of PS and practical guidance. This is relevant to all the points of the current research.

Addington-Hall (2007) suggests that satisfaction with living conditions – general life satisfaction – is connected to personal behaviour and is directly influenced by the living conditions themselves as well as perceived and evaluated attributes. As Sandoval, Brown, Sullivan, and Green (2006a) argued, the attributes that patients most commonly identified as being relevant to their overall satisfaction are patient access to information, interpersonal doctor-patient interactions and coordination of care. The least important factors are waiting times, pain-, and symptom management.

PS depends on objective (e.g. education, income, gender) and subjective factors (e.g. emotion, cognitive factors), as mentioned in the section about QOL. These factors can be patient-, treatment-, or disease-related (Addington-Hall, 2007). Mathews, Ryan, and Bulman (2015) identify in their research that PS depends on a physician's interpersonal skills, coordination of care and timeliness of care. In a qualitative study, Mathews and colleagues conducted sixty semi-structured interviews with patients with different cancer diagnoses to determine which factors affect patient satisfaction/-dissatisfaction with waiting-times. Unlike Mathews' study, this research reduced the heterogeneity of the sample group and only studied patients who had the same form of cancer. This research also focused uniquely on a single provider in one outpatient medical practice rather than on multiple different outpatient units. The findings of Mathews et al. (2015) are nonetheless relevant for the current study because they present similarities to Kleeberg et al.'s (2005) study, which also focused on interpersonal skills such as patient-doctor-communication and coordination of care.

Satisfaction with doctor-patient communication, shared-decision-making and treatment decisions are influenced by the personal attitudes of patients and are key factors of the PASQOC study of Kleeberg et al. (2005). This study showed that PS with information about the diagnosis, treatment side effects and emotional aspects of communication with treating doctors lead to higher satisfaction and acceptance among the patients. These two studies are pertinent to the research performed in this thesis. The topics raised by these researchers will be further discussed in the chapters to follow.

The qualitative study of Hitz et al. (2013) from the Swiss Oncology Network researched the idea that decision-making and satisfaction with treatment decisions are important parameters of PS in oncological treatment. This is of interest for the researcher of this thesis as Hitz et al. s (2013) predictors for satisfaction with treatment decision, shared-decision making and QOL indicators are significantly associated with the current study.

Tüllmann (2015) sees the term satisfaction as being associated with the fundamentally different circumstances of individuals, who can be either satisfied or dissatisfied. When aspects of QOL are modified, this leads to increased satisfaction or dissatisfaction. For the evaluation of his quantitative data, Tüllmann (2015) developed response categories of satisfaction, QOL, good life, happiness and wellbeing. When collecting his data, Tüllmann (2015) only focused on word counts with sum-scores rather than rating the meaning of the patient statements. It is here where the researcher of this thesis diverged from Tüllmann's method. To gain a deeper understanding of patient statements, the researcher assigned every patient answer with a value to emphasise the importance with which patients endowed particular topics.

Quality of life researcher Cummins (1996) states that subjectively perceived satisfaction leads to higher personal satisfaction scores because people usually feel good about themselves. Consequentially, perception of satisfaction is influenced by external factors other than just those that affect PS. Having established this, it seems impossible to predict the relationship between external conditions and subjective PS. PS is an important component of health care supply and can be used to improve quality management features (Weißflog et al., 2014). Weißflog et al.'s (2014) research centres on a particular type of in-depth interview – the so-called dyads-interview – which is given to cancer patients during their aftercare.

This thesis determined that the issue of follow-up care has neither been resolved under the current health care oncology contract nor under the new ASC model. This much-neglected facet is an essential aspect of QOC for cancer patients but is not included in this research.

However, Sitzia and Wood (1997) point out that satisfaction is also a comparison between nominal and actual status: what patients expect to experience and what they experience. These researchers have published many papers on nursing care and incorporate PS and patient opinions in their research. Interestingly, Sitzia and Wood (1997) support the idea that the more a doctor's service meets the expectations of patients, the more a patient's satisfaction level will increase. This idea is tested in the current research project, which examines the theory that patients with lower expectations tend to be more satisfied (Goldzweig et al., 2015).

Others have suggested that PS or dissatisfaction can be primarily evaluated with quality management parameters such as structure-, process- and outcome parameters (Donabedian, 1966). According to Donabedian's (1966) framework for health care, it is important to evaluate these quality parameters to understand PS better. Evaluation of PS can be seen as a technical or practical process (e.g. onco-

logical drug treatment), the evaluation of organisations (e.g. outpatient and inpatient care), evaluation of health systems (e.g. new health care model), or evaluation of care (e.g. care of patients with chronic diseases). PS studies have proved valuable in all of the fields mentioned above (Fitzpatrick & Hopkins, 1983). These parameters of PS can be used to improve the QOC and detect weak points in health care systems.

In the quality assurance process, which is derived from the quality of patient service, treatment and health outcomes, it is important to know how satisfied the patient is, because a compliant and cooperative patient is more likely to follow the requirements of treatment than a dissatisfied and stressed patient (Nathorst -Böös, Munck, and Ekfeldt - Sandberg (2001). Nathorst - Böös et al. (2001) built on the ideas established in Donabedian's framework, focussing on quality from the patient's perspective with the use of quality models. They conducted 35 interviews involving all sectors of care to evaluate dimensions of QOC, such as the organisation of care and care from the patient's point of view. To encompass the many different aspects of care, Nathorst - Böös et al. (2001) also had participants fill out a questionnaire. The idea of combining interviews and questionnaires in one research approach was very influential for this thesis, which also implements these two methods but treats the questionnaire uniquely as an add-on to the interview. It is important to note that this research does not adopt a mixed-method approach but looks on similarities and differences in how patients answer questions in both methods.

Also of interest is the study of Baumann et al. (2008). These researchers also focused on the patient perspective, but specifically on references to medical treatment and patient-related outcome. In this study, the researchers had 15,272 German patients from 147 different outpatient practices come to the Scientific Institute for Haematologists and Oncologists in Private Practices (WINHO) in Cologne and fill out quantitative questionnaires. This WINHO research, along with Kleeberg et al.'s (2005) PASQOC study, are key sources of literature for this thesis. Both projects examine PS and QOL from the perspectives of surveyed patients, doctors and medical practices. However, this research adopts a qualitative method rather than a quantitative method and seeks to discover the quality of oncological care in a single outpatient unit.

A difference in the results of the PASQOC and WINHO studies is that the PASQOC study rated the amount of information material in waiting rooms as being important, whereas Baumann's study did not. As well as the issues with telephone access and waiting times regarding patients who have had bad experiences in

these cases, Baumann suggests that further studies focus more energy on emotional aspects that are sometimes ignored in quantitative methods such as trust in the doctor-patient relationship and good doctor-patient-communication.

Kleeberg et al. (2005) argue that the patient—doctor-relationship greatly influences PS. This is supported by other researchers such as Möller-Leimkühler, Dunkel, and Müller (2002), Sandoval (2006b), Davidson (2005), and Bredart et al. (2005), who argue that satisfaction with doctor-patient communication and joint decision making are key elements of QOC.

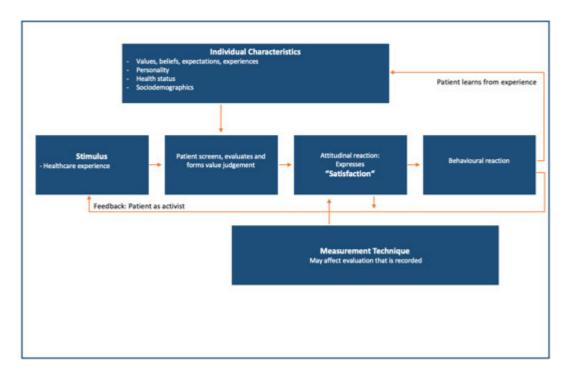
Hermes-Moll et al. (2015) performed a quantitative, multicentre study in which patients were asked to fill out questionnaires. Out of these questionnaires, Hermes-Moll et al. specified 46 quality indicators. In a previous research study, Hermes-Moll (2013) worked with the WINHO institute to form a multi-stage peer-to-peer action with oncologists in outpatient practices. This identified quality indicators focused only on process indicators. No outcome indicators were developed because the survey was given out over a long period with unclear classification from good and bad results. The feasibility of quality indicators in everyday practice was tested based on patient records. Because the study was time-consuming, and the different forms of documentation provided by the many participating doctors were not homogenous, less than 30% of the data gathered in the study could be used. It seems, therefore, that this method is not suitable as a prompt and practicable tool to determine the quality of oncological care.

It is, therefore, necessary to look elsewhere to find other quality aspects that influence PS in healthcare and can determine what influences patient opinions and behaviour when they are undergoing treatment. Elkin (2007) conducted structured interviews with seventy-three patients to perceive how much patients wanted to be involved in the decision for the cancer treatment process. Indeed, Elkin (2007) explained that a quarter of cancer patients believe in relying upon the conclusions of their physicians without providing input of their own regarding treatment options. Prognostic information, patient activation such as participation and involvement in the treatment process, and decision-making preferences are not easy to predict. That said, Elkin (2007) suggests that explicit patient-doctor communication can help to filter a patient's preferences and improve the satisfaction of patients as they undergo their treatment process.

Furthermore, Brinkmann et al. (2007) suggest that to be well-informed means having personal opinions about - and a say in - treatment options. Bruera and al. (2001) propose that age plays an important role in this statistic. Their study suggests that 50% of younger patients prefer more collaborative decision making when it comes to medical care. Both studies draw attention to limited insights in

diagnosis and treatment. It is therefore important to understand that individual patient characteristic, personal situations and healthcare settings can all influence the satisfaction of patients with the provided healthcare. This is illustrated below in Strasser, Aharony, and Greenberger (1993)'s conceptual framework (see FIGURE 4), one of the first holistic models pertaining to PS with healthcare based on Pascoe (1983) model, who views PS as a valuation of the services that consumers get (Strasser et al., 1993). Strasser et al. (1993) augmented Pascoe's model with individual patient values, beliefs, expectations and personal attributes. Strasser et al. (1993) and his team took into account patient backgrounds as well as their social and demographic profiles in addition to their current health status. The components of this comprehensive model describe what is necessary for physical and psychological well-being.

FIGURE 4: HOLISTIC MODEL OF SATISFACTION WITH HEALTHCARE (ADAPTED FROM STRASSER ET AL., 1993)



Garratt, Schmidt, Mackintosh, and Fitzpatrick (2002) and Gesell and Gregory (2004) have reported on patient experiences with ambulatory cancer care. These researchers strive to identify assessment features that could be used to define and measure PS with care. Garratt et al. (2002) complain that numerous QOL measurements exist but that in general, there are no established QOL standards. On the other hand, they stated the great importance of measuring health outcomes to evaluate the quality of health care as a recommendation to determine the most applicable procedures for individual implementation.

Gesell and Gregory (2004) provided several practical suggestions about how to improve QOC for cancer patients. A key point proposed by Gesell and Gregory that is relevant for this thesis is that a health care provider's behaviour and attitude can change the quality of service as well as patient perceptions of the healthcare that they are receiving. This emphasis on the interpersonal is one of the key points of this study, which seeks to find ways to improve outpatient cancer care by implementing continuous quality improvement and increasing PS.

Fitzpatrick et al. (2006) examined different health care evaluation instruments (e.g. SF-36 questionnaire, EURO-QOL, FACT), both generic and disease-specific, intending to assess how these instruments report on patient perceptions of care. Fitzpatrick and colleagues reviewed a large number of patient-reported health instruments for people with different diseases. Like Garratt et al. (2002), they point to the importance of having instruments that can report on emotional needs, stressing that uncertainty and anxiety accompany and influence many other health-related problems. Fitzpatrick et al. argue that PS is determined by socially created expectations (e.g. cultural differences). Both studies suggest supplementing traditional measurements and quantitative data with qualitative studies that examine the opinions of both patients and physicians.

Sitzia and Wood (1997) identified various models which suggest that PS is not only determined by demographic, social and psychosocial features. Glatzer (1984) and Gesell and Gregory (2004) assert that a patient's satisfaction is affected by both environmental and personal variables. The results of this work are relevant for understanding how and in what ways PS is influenced and what instruments best work for research in this field. Additionally, Weißflog et al. (2014) define several features of PS from the PASQOC study that examine patient characteristics such as age, gender, working conditions, tumour diagnosis and function status. The interview questions for this research expanded upon the items addressed in the PASQOC study. The added questions dealt with key topics such as living conditions, institution recommendations and trust in the doctor and team.

PS is a multidimensional construct and several studies have been ambiguous in their findings. Al-Abri and Al-Balushi (2014) focussed on quantitative approaches with standardised questionnaires to measure PS based on demographic factors. They also reviewed other studies to identify influential attributes of PS to improve quality in healthcare. Al-Abri and Al-Balushi (2014) stated that health condition is an important predictor of the overall satisfaction of patients but is only marginally influenced by age, gender and education. In contrast, Nguyen Thi et al. (2002), Nguyen et al. (2011), and Jenkinson and al. (2002) declare that old age and better health status correlate with higher satisfaction. Bleich, Özaltin, and Murray (2009)

identify more external factors (health status, immunisation, types of care) that influence PS with health care. However, Fitzpatrick et al. (2006) point out that these single surveys about QOC are not sensitive to specific issues pertaining to patient experiences of care and satisfaction.

It is important to note that the influencing features of care and the preferences and expectations of patients remain undetermined. On the one hand, PS is recognised as a key factor in assessing oncological QOC. If patients are satisfied with the care they are receiving, it may influence their adherence to medical treatment and influence outcome. Nonetheless, it is hard to identify the subjective patients' needs and expectations as well as the influencing features of care.

In summary, patients with cancer diseases require high QOC and have expectations that must be considered in a continuous quality improvement process. Doctor-patient-relationship, participative decision making, communication and support are vital features of PS because the integration of patient perspectives in healthcare decision-making improves the overall QOC.

This research will demonstrate that QOL and PS research are essential when asking patients to report on aspects of their experience of care and their needs. If the results from the patient-reported health-related QOL and PS reveal relevant limitations or deterioration, this could indicate a concrete need to improve the QOC.

#### 2.4.3 The term quality of care

This research aims not only to collect information about the objective effects of patient treatment but also to evaluate their subjective impact on patients. Objective factors have been evaluated since the 1990's by way of the SF-36 (Ware et al., 1995) and EORTC questionnaires (Groenvold, Klee, Sprangers, & Aaronson, 1997). These generic questionnaires evaluate disease- and treatment-related symptoms as well as physical, social and psychological factors. In addition to the questionnaires (see further explanation in chapter 4 methods), several quantitative supplementary questionnaire modules have been developed in the last 20 years. These illness-specific questionnaires are cancer site-specific and evaluate QOL and doctor-patient communication (Velikova et al., 2008). The findings of Velikova et al. (2008) underline the importance of flexible, personalised assessment instruments. For this research, Velikova et al.'s (2008) research is a valuable starting point because their study explores what doctors in oncology and patients expect from a QOL questionnaire, the clinical benefits of these instruments and how to develop the tool for better use in medical practices. Velikova et al. (2008) combined the EORTC- disease-specific standardised questionnaire with a focus group interview (8 to 10 patients in one group). Eight groups of patients being treated by 32 oncologists were interviewed. The results of this study went into the development of two key sets of questions. One set was disease-specific and aimed to be used for comparisons over time, and the second was a reduced set that could be used during visits to focus on the individual issues of patients. Interestingly, Velikova et al. (2008) separated the standardised cancer questionnaire into site-specific, treatment-specific and individual patient-specific measurements. This qualitative research approach could play a significant role in generating data from clinical practice and could be used to develop a tool to evaluate the QOL of oncological patients.

Over the years, illness-related questionnaires have slowly begun to focus on areas of health-related QOL and patient-reported outcomes. The term outcome depends on the perspective of the user in the context of health care supply. As Andresen and Meyers (2000) point out, additional and specific testing is required to measure the HRQL of patients who suffer from diseases other than cancer as well as heterogeneous groups of patients with impairments.

Blazeby (2001) focused on patient choice and the information provided for patients in different areas of HRQL. Blazeby (2001) considered so-called "hard endpoints" such as morbidity data, overall survival and response rates to be inadequate for evaluating the QOL of oesophageal cancer patients. Instead, she suggested examining other aspects including psycho-social well-being, general health perceptions and QOL as a patient-based measure of outcome. Blazeby's (2001) views correspond to those adopted by the current study, which prioritises patient information and shared decision making over hard facts.

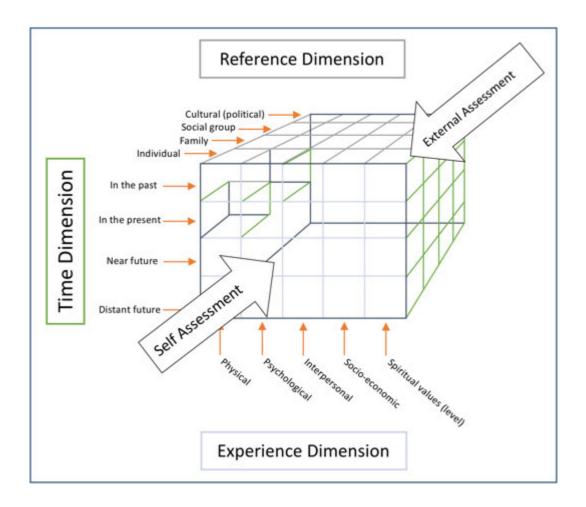
The term QOC is multifaceted and intangible. Its many indirect indicators include disease-, treatment-, and symptom-related factors. This research adopts the perspective that multidimensional profiles cannot be evaluated only by quantitative questionnaires because of the difference between generic- and illness-specific procedures (Appendix B: TABLE 50: Benefits and drawbacks between generic and illness specific procedures (own drawing)). This research evaluates patient experiences by combining subjective observations with verbal descriptions to compare objective and subjective factors better.

It is important to bear in mind that it is possible to misinterpret the reliability and vulnerability of the chosen approach. In their study, Hammersley and Atkinson (2007) attempted to combine quality criteria with a constructivist methodology to produce validity, credibility, trustworthiness and relevance. According to Flick (2014) and Mayring (2014), the quality criteria in qualitative research are linked to

special conceptions of content-analytical-quality criteria and triangulation (which are explained in detail in the methodology and the methods chapter (see 3.4.4 Quality criteria). As already mentioned, triangulation serves as a quality criterion of validity. As Mays and Pope (2000) point out, triangulation could be one way to improve validity in qualitative health care studies. Comparing two different methods can compensate for the weaknesses of one single method. Mays and Pope (2000) also see triangulation as a comprehensive and reflective form of data analysis and not solely as a test of quality criteria. In this research, the method of triangulation is used to compare perceptions of PS in interviews from two groups of patients being treated under different health care models.

The QOL cube, developed by Küchler and Berend (2011) (see FIGURE 5: Quality dimensions in oncology, model (adapted from Küchler & Berend, 2011)), connects the psychological, interpersonal, social, economic and spiritual dimensions of QOL. A person's QOL is determined by their personal experiences, their life history and time. The distinction between the near and distant future plays an important role for therapy indication and information. Patients who do not suffer from life-threatening diseases accept a short-time loss of QOL, but they are not free from normal and other restrictions (cultural, social, individual etc.) Consequently, it is essential to provide patients with the necessary information that allows them to perform self-assessments of QOL and participate in decision-making. The dimensions displayed in Küchler and Berend's (2011) model form the basis of how QOL is viewed in this research.

FIGURE 5: QUALITY DIMENSIONS IN ONCOLOGY, MODEL (ADAPTED FROM KÜCHLER & BEREND, 2011)



The model of quality dimensions developed by Küchler and Berend (2011) places objective factors (aforementioned) and subjective factors such as emotions and cognitive functions side by side. Objective and subjective factors determine a patient's total satisfaction (Allardt, 1973). This means that PS must be considered when researching QOL but is also independent of QOL. As Küchler and Berend (2011) argued, the term QOL and related assessments of QOL have now become standard in clinical trials and oncological practices in in- and outpatient care. Trust in doctor-patient-communication and compliance or adherence is always relevant to assessments of QOL. A doctor must find ways to communicate with a patient that is not only based on facts to create a positive doctor-patient relationship. However, one can never forget when researching QOL and QOC that human beings react differently in various situations. Correspondingly, patients assess their QOL differently when they fill out questionnaires. Only extensive therapy studies with large patient pools can achieve statistically relevant data. As this research has a minimal sample size, it is not based on statistical evidence.

Questionnaires alone cannot effectively perceive a patient's emotions, attitudes and conditions. The subjective dimensions of QOL and PS cannot be evaluated objectively merely by way of surveys (e.g. housing conditions, family relationship, earnings, family status, social and physical well-being). When assessing QOC, self-assessment tools are usually used to evaluate QOL and PS. It is important to note, however, that a patient's mood at the moment of evaluation is significant for determining their QOL and PS in these circumstances (Schwarz & Hinz, 2001). All dimensions of QOL, PS and QOC are shown in FIGURE 6, which depicts the items considered when creating the interview questions. These items, which are discussed at great length in the following chapters, became the so-called subnodes that were evaluated in the interviews and that were grouped into the categories of interpersonal, medical and organisational items.

FIGURE 6: QUALITY OF LIFE, PATIENT SATISFACTION AND QUALITY OF CARE DIMENSIONS IN ONCOLOGY (OWN SOURCE)

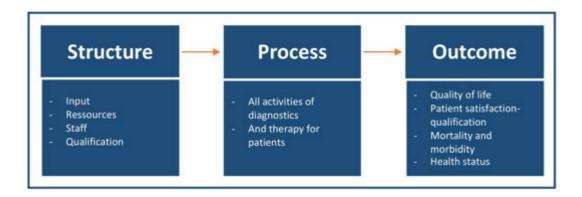


The literature search revealed several studies that assessed QOC in oncology settings (Bredart et al., 2015; Gourdji, McVey, & Loiselle, 2003; Hoberg, 2011; Wintner et al., 2012). Lohr and Schroeder (1990) define QOC for patients as the possibility of preferred health outcomes and the provision of care that is consistent with the current standard of knowledge. They believe that any quality assessment should pay close attention to the doctor-patient-relationship and that the decision-making processes should expand health and QOL, PS and outcomes.

For the researcher in the current study, Lohr and Schroeder's (1990) musings are pertinent because asking what can ensure quality is also one of the questions posed in this study. Lohr and Schroeder's (1990) research is based on the concept of Donabedian's (1988b) quality assurance model. It is necessary to understand the structural context in which care is given, the processes of care and the outcomes of care, to define QOC in a quality assessment process. Donabedian (1980) divides these factors into three elements of quality of care: process-, structure-, and outcome (see FIGURE 7: Evaluation of health services. Dimensions of quality. Model adapted (Donabedian (1980).

Structures of care refer to the facilities, equipment and services provided by health professionals. The process refers to the procedures undergone when providing care for patients. The outcome of care represents the changes in disease, physical and emotional functioning of patients, patient satisfaction and compliance with medical care that come as a result of treatment (Gupta, Granick, Grutsch, & Lis, 2007). Gupta et al. (2007) stated that HRQOL tools provide prognostic information that is relevant for further treatment and outcome in health care. The studies of Lohr and Schroeder (1990) and Gupta et al. (2007) clearly show that it is necessary to develop a tool that can quickly and rapidly provide the information about PS and QOL for treating oncologists. A possible result of this thesis could be the development of such a tool.

FIGURE 7: EVALUATION OF HEALTH SERVICES. DIMENSIONS OF QUALITY. MODEL ADAPTED (DONABEDIAN (1980)



There is a growing interest in defining and improving the QOC in healthcare systems. This requires a systematic understanding of the factors that influence healthcare outcomes (Sandoval et al., 2006b). Sandoval et al. (2006b) state that the outcome represents the effects of care on the health status of patients. Improvements in the patient's understanding and beneficial changes in the patient's behaviour are included under the broad definition of health status, and so is the level of patient satisfaction with the QOC.

Zapka et al. (2003) point to several factors that impact the processes of care. They developed a conceptual model to identify the types of care that correspond to different cancer entities. The study produced several types of health care outcomes that can be used as indicators of quality of care. These include functional, emotional and social status, perception, satisfaction, and death (Zapka et al., 2003). This has changed as prognosis has improved significantly. However, Brook, McGlynn, and Cleary (1997) point out that death is an expected outcome parameter for many chronic illnesses such as malignant diseases, and that a reduced outcome parameter reflects neither good nor poor QOC. Brook stated his quality assessment methods in the light of Donabedian's (1988b) seminal work.

A valuable way of improving QOC is determining what is most important to patients in order to improve PS and QOL. Skarstein, Dahl, Laading, and Fossa (2002) identify process and structure attributes which can be used to evaluate QOC. Firstly, they recommend identifying the patient's overall perceptions of QOC. This can be done by providing patients with adequate information about, e.g. diagnosis and treatment decisions. Secondly, they suggest that waiting-times are significant predictors of overall satisfaction and can, therefore, also influence QOC. Gourdji et al. (2003) and Gesell and Gregory (2004) prioritise waiting-times for improving PS with outpatient cancer care. In the last 25 years, Blanchard, Labrecque, Ruckdeschel, and Blanchard (1990) have focussed on process elements: physician behaviour and patient perceptions.

Ware (1983) used a special PS questionnaire, the short-form (SF-36), in his study. The SF-36 comprises questions regarding the health care provider and the services delivered. The technical and interpersonal skills of the doctor are assessed along-side patient satisfaction with care. This questionnaire identifies five different dimensions of PS: 1. technical competence, 2. communication skills, 3. interpersonal skills, 4. accessibility of care, 5. continuity of care.

This thesis uses a similar questionnaire, analogous to the short-form-12 questionnaire, which also examines these five dimensions. It is important to note that in one single outpatient unit, it is not possible to perform reliable quantitative research because of the small number of participants, the high costs and the lack of resources. Therefore, this questionnaire is only used in this qualitative study to compare the relevant topics with the interview questions and to look for similarities and differences between different approaches. The interview questions cover a range of subjects, including patients' perceptions of care as well as PS with care, demographics (gender, age, family status, distance to practice, and social status), disease and treatment history.

Bredart et al. (2015) point out that important aspects of care are often missed in current questionnaires and interviews in outpatient settings. The authors focus on the patient perspective as an important indicator of QOC. Bredart et al. (2015) rue the fact that several questionnaires lack important information about psychometric and cross-cultural comparative assessments. They state that the PASQOC questionnaire, on the other hand, is very relevant to cancer outpatient care.

In addition to this, Spinks et al. (2011) complain that current studies lack measures that integrate the patient's point of view. Spinks et al. (2011) devote their research to looking for gaps in endorsed measurements for outcome-, structure-, and process measures divergent to their applicability to the related disease. They suggest a specific model based on the targeted measurement of patient-reported outcome key factors to facilitate meaningful procedures.

In summary, this study takes the patient's point of view and preferences into consideration. Furthermore, it uses process and outcome parameters to provide valid information about the QOC in a single outpatient unit. The information obtained could be used to improve QOL and PS. All aspects of QOL, PS and QOC are factors which are influenced by the patient-doctor-relationship and decision making. This research adopts the perspective that all three elements of Donabedian (1980) process-, structure-, and outcome parameters are useful for monitoring the QOC. The concepts of QOL, PS and QOC assessed in the literature review were used to form the semi-structured interview and the analogous standardised questionnaire (SF-12). The SF-12 is a well-established short-form survey with 12 questions originally developed from the SF-36 by Ware et al. (1995). In this research, the chosen questionnaire was adapted to the three categories: physical and psychological well-being and painlessness. Due to the minimal answer options, the aspects of social life and role functioning were allocated to the category of psychological aspects (see p. 154 section: Decision for the chosen questionnaire).

#### 2.4.4 The term quality management in oncology

It is important to elaborate upon the relationship between quality management and keywords (QOL, PS, QOC, ASC) that are discussed in this literature review to clarify the term quality management (QM) in oncology. Donabedian (1980) defined quality with his threefold approach of structure-, process-, and outcome. Leicht, Honekamp, and Ostermann (2012) define quality as a management instrument that aims to optimise processes and obtain and develop quality. Leicht et al. (2012) performed a case study report in 2012 to document the impact of PS in quantitative research on improvement in a quality management system in a specialist practice.

According to these researchers, quality can be used to obtain the following results:

- 1. Optimising medical guidelines
- 2. Improvement of PS
- 3. Efficiency of resources

Essential medical and organisational processes can be structured and planned with a functional quality management system (Donabedian (1980). The mandatory introduction of QM systems in Germany was established in 2010 (Meißner & Rieser, 2012). The issue, Meißner and Rieser (2012) argue, was the communication of quality which stems from business-related sources in the outpatient medical practices. Each disease and every individual case must be determined in advance with medical and other quality features. The focus of interest in this study is the continuous quality improvement (CQI) process from Donabedian (1980) through constant and regular review of the outcomes. In this thesis, the researcher also uses quality management parameters to review quality in a single outpatient practice.

Physical, emotional, and treatment-related quality aspects were selected from patient interviews, the literature and specific health-related QOL questionnaires. The importance of medical supply quality is measurable with patient-reported health questionnaires, e.g. generic health instruments, the SF-36 and SF-12 (Fitzpatrick et al., 2006). Maxwell (2012) broadened the scope of QM with his six dimensions of quality to evaluate medical supply quality (see TABLE 6). Each of these dimensions should be recognised and requires different tools for an assessment. Maxwell's dimensions correspond with valid quality criteria.

TABLE 6: MAXWELL'S SIX DIMENSIONS TO EVALUATE QUALITY

Efficacy	Accessibility	Efficiency
This quality criteria evaluate if an institution achieved the best results or earnings with the smallest number of funds. Ability of the health system to improve health.	The determinant "access" follows the aspect of every patient who required information or support, and if the supply had been affected. Quality management aspects in my research look on outcome and treatment quality parameters in the interview phase.	Ability of the health care system give optimum results at the lowest possible costs
Acceptability	Relevance	Equality
"Good quality", means the acceptance by patients and in social context. In relation to my research guarantee of information, interdisciplinary contact and multimodal therapy concepts. The needs and expectations of patients in relation to structural and process orientation.	Optimality – the most advantageous relation between cost and benefit.	A faire distribution of health care services in the society

The ultimate aims of this study are to describe several approaches that compare quality management features and to suggest ways to improve PS and QOL in order to improve QOC. Klindtworth, Cuno, Schneider, and Wehkamp (2010) point out that quality management systems need standard quality criteria for efficient use of resources. Klindtworth et al. (2010) qualitatively interviewed 19 patients in a palliative care ward to see what factors contributed to the satisfaction of patients and family members. Their study focused on developing a practical quality management process to improve satisfaction and interpersonal communication in palliative care. Klindworth et al.'s (2010) study is an excellent example of how qualitative research can improve subjectively experienced PS promptly before patients come to the ends of their lives. Klindtworth et al. (2010) also indicated that quantitative questionnaires are often inferior to qualitative interviews because they sometimes have a low response rate and because quantitative parameters are not always applicable for a patient's situation. The literature presented below evaluates quality management criteria in health care.

It is first necessary to define quality management in the context of the outpatient setting. Maxwell (1984), one of the first authors on this topic, defined the core components of care and suggested that quality in health care has six dimensions. The idea of evaluating these core dimensions was later built upon by researchers

such as Donabedian (1980) and Gerteis (1993). The definition of quality is important for the implementation of quality assurance procedures. In order to achieve progress and documentation, readily available quality parameters are necessary (Maxwell, 1984).

Dröschel, Stendera, and Imkamp (2017) focus on cost-effectiveness, quality of treatment and care from the patient's point of view in their evaluation of quality management. These three main perspectives are significant because Maxwell (1984) did not advocate focussing on patient perceptions in his dimensions of health care quality. As mentioned before, it is relevant to quote Donabedian's (1980) definition of quality when examining causal relationships from the patient's point of view in the health care system. Quality can be understood as an evaluation of the structure in which care occurs, the process of care and the outcome attributes of care. In a social context, the concept of quality represents the patients' expectations regarding their relationships with caregivers and patient views about the responsibilities of the health care system. It is important to understand that quality as structure-process-outcome parameters is not the only attribute we can choose that can improve the QOC.

According to Linder-Pelz and Struening (1985), PS and positive attitudes are based on distinct dimensions of health care, such as access to treatment, cost-efficacy and efficiency. Attitudes in Linder-Pelz and Struening et al.'s (1985) model are defined as being affective and perceptive. Affective refers to the emotional evaluation and perceptive to cognitively based evaluation to the structure, process, and outcome of service. Interestingly, the structure parameters in relation to the appointment and waiting times in this study meet the highest dissatisfaction rates according to results from Kleeberg et al.'s (2005) study who point to organisational weaknesses as a result.

Pascoe (1983) defined patient attitudes in the context of health care as being grouped into three categories: personal attitudes, attitudes influenced by the so-ciodemographic context, and health-related behaviour. Personal attitudes have to do with patient expectations of and opinions on medical care. Attitudes influenced by the sociodemographic context can be linked to a patient's personal background. Health-related behaviour pertains to a patient's adherence to treatment and reactions caused by a patient's illness. These categories are relevant to this research because the study takes patient opinions, expectations and satisfaction with life into account. Inspired by Pascoe's (1983) QOL attributes, this study is based on three main categories: physical, psychological and interpersonal well-being.

Many different approaches have been used to collect data regarding QOL and PS. In 2014, Al-Abri & Al-Balushi drew attention to the many process-oriented quality management systems that exist. It is important to focus on different quality management aspects in oncology in order to specify what process-oriented quality management means (Wild & Patera, 2013). Firstly, it is necessary to examine medical treatment aspects in terms of guidelines and measurements of quality management in everyday cancer care. Secondly, it is valuable to consider the effectiveness and relevance of quality management. Thirdly, it is important to focus on communication and decision making from patient perspectives (Chassin & Galvin, 1998). Bruns, Wesselmann, Mugele, and Kowalski (2016) discuss the idea that inter-sectoral networks and collaborative arrangements in cancer treatment can be used to achieve improvements in the quality of healthcare. It is reasonable to assert that this networking and collaboration between doctors was the idea that led to the modern-day model of ASC.

Established quality management systems in outpatient units show improved organisational and treatment processes which contribute to continuous quality improvement (CQI) (Auras et al., 2016). The main aim in Auras et al.'s (2016) research is the four PS scales on medical-, information-, interaction-, and professional competence. An extensive quantitative study was performed by Auras in 2016 to identify the multiple factors of PS. It remains unclear what patient-related and practice-related factors most affect the satisfaction level of patients undergoing ambulatory care. The study of Biermann and Küchler (1999) also discussed the importance of the quality management aspects in health care and the concept of QOL. While evaluating CQI, Biermann and Küchler (1999) determined that QOC is not only based on structure and process quality but can also be analysed by way of objective and subjective endpoints of the outcome.

Gourdji et al. (2003), building on the ideas of Biermann and Küchler (1999), used reliable and measurable key indicators such as PS to ensure CQI for oncological patients requiring outpatient services. Baumann, Buschmann-Maiworm, and Schmitz (2012) introduced the so-called quality indicators, which rate as the "gold standard" for process quality management aspects. These quality indicators can be defined as standardised quantitative data consisting of specific quality criteria based on patient satisfaction questionnaires and outcome parameters. The aim of Baumann et al. was, alongside other qualitative supply criteria, to transfer the construct into a measurable "countable" one based on the international RAND/UCLA expert assessment. The quality indicator system consists of five modules: basis documentation, therapy, pain, palliative medicine, psycho-social well-being and two tumour entities. A limitation in Baumann's study is the more medical unilateral structure of the expert panel. The feasibility to obtain and generate data could

be an issue. Baumann, & Steinmetz, H. T. (2010) refer to the WINHO institute as a domain of health service research. The investigation of quality management concepts in the ambulatory care of cancer patients as well as the development of quality criteria are extremely important for oncologists.

Hensen and Hensen (2010), on the other hand, focused on benefits such as perception, control, confirmation from the patient's perspective. These researchers enlarged the traditional system-related quality dimensions of structure-process-outcome into a subject-related perspective focusing on the quality of a relationship, user and patient competences, and individual experiences.

In conclusion, quality management in health care systems represents a sufficient and appropriate (in terms of QOL and PS) degree of care that aims to fulfil the patient's desires and requirements regarding their health status (Dröschel et al., 2017). It is important to refer to four main perspectives of supply in health care: the individual patient perspective, the quality of processes and economic resources, and quality in medical areas. These aspects were considered in this chapter in discussions of the keywords chosen for this study. The growing diversity in health care and the complexity of treatment of severely ill patients was the researcher's motivation to improve the interactions between participants and treating doctors.

This research also aims to improve the QOC through optimising structure and processes in patient-centred care as opposed to a quantitative approach. The current research also argued that the debate "qualitative or quantitative" is not either-or but rather: could different approaches be combined and adapted to the needs of the practices and patients? These desired requirements and expectations in quality management systems may be considered as implicit from the patient's point of view. Due to the severe diseases of the patients who display a more significant heterogeneity, a representative approach is challenging to reach. Consequently, the concept of quality management in oncology aims to fulfil the desires of the patients and to improve their treatment results with structural guidelines. This is relevant to this research, which discusses quality management aspects related to PS, QOL and QOC in an outpatient unit.

#### 2.4.5 The term ambulatory specialised care

This research examines the relationship between PS, QOL and the QOC for patients undergoing oncological treatment in a single outpatient unit. It also expands the limited body of knowledge relating to the perceptions of quality of care among patients who are being treated under the new ASC healthcare model. A new supply area in health care was established based on severe, life-threatening diseases

of oncological patients. ASC is also enforced in other medical fields, but this is not examined in this research.

While structures for quality assurance in oncology exist, so far, a standardised quality approach for evaluation of QOC and interdisciplinary teamwork has not been developed. As shown in Maxwell's figure 4, it is necessary to clarify whether the new ASC model can be beneficial to patients and how it compares to the previous health care oncology contract model in an outpatient setting. On 20.02.2014, the Federal Joint Committee (G-BA) approved the guidelines of ASC for the treatment of gastrointestinal tumours (Klakow-Franck, 2014a). Klakow-Franck (2014a) refers to the fact that having patients be more involved in this process and participating in decision making contributes to QOL. The author also points to the need for comprehensive care that is close to home and interdisciplinary teamwork between in- and outpatient medical supply.

ASC represents a new, transparent, interdisciplinary and cross-sectoral form of collaboration between in- and outpatient care (Jaeckel & Da-Cruz, 2015). These authors argue that the main idea of ASC is to optimise and establish supply structures. The treatment of complex diseases in an interdisciplinary, cross-sectoral manner is one of ASC's characteristic features. Another feature of ASC is the establishment of an interdisciplinary tumour-conference. This means that cooperation between physicians from multiple disciplines discuss patient cases on a so-called tumour-board (round-table meeting).

Management of quality assurance can usefully improve ambulatory care (Bredart, Coens, & Aaronson, 2007). Bredart et al. (2007) have focused on recent studies on improving doctor-patient communication to improve the quality of care. German lawmakers attach great importance to the subject of quality. As Gerlach (2012) points out, quality reflects how quickly innovative structures and processes can be implemented in supply care. Innovative structures and processes greatly influence treatment results. This work focuses on the quality of processes and on standards in a quality management system that is bolstered by the new, innovative health care sector of ASC. ASC is intended to provide cross-sectoral health care that combines in- and outpatient care. Concerning structure and process quality, Butterwegge et al. (2013) speak in favour of the interdisciplinary approach, which is when doctors from different fields work together to treat patients suffering from severe and chronic diseases. In order to improve existing quality features, ASC builds on already established networks and cross-sectoral cooperative structures (Butterwegge et al., 2013). One key point of ASC is that it requires mandatory cooperation between all health care providers (Butterwegge et al. (2013). The role played by patients in the new ASC model is not clearly defined.

In contrast to the existing oncology contract model is patient information about the treatment process and the mandatory confirmation considered. A special report from an expert panel in 2012 focused on the inter-sectoral boundaries between in- and outpatient centred care (Gerlach, 2012). This report analysed whether and to what extent competition between hospitals and outpatient specialists can improve the efficiency and effectiveness in the health care sector. The transition from in- to outpatient care was one of the chapters in the report, which evaluated the issues of cross-sectoral care. Interestingly for this thesis, the report considers how information and communication could remove or reduce the disadvantages of inter-sectoral boundaries. Another study by Degen, Möller, and Schlechter (2014) addressed these issues of PS and inter-sectoral problems. Their research concluded that inter-sectoral collaboration provides more satisfaction, especially when it comes to patient trust in the physician. Also, time constraints and psychosocial factors are relevant influencing factors from a patient's point of view. Degen et al. (2014) mention that ASC is a quality feature in oncological treatment. The focus on psychosocial factors is of crucial importance for patients' perceptions of satisfaction.

Quality management and quality features meet the requirements, needs and economic aims of patient-centred care at a high level (Fitzpatrick et al., 2006). Patient-centred care is recognised as a measurement of QOC for patients who are affected by chronic diseases such as cancer (Harrison, Young, Price, Butow, & Solomon, 2009).

Quality management, which is influenced by QOL, PS, QOC and cross-sectoral collaboration, must be considered as the key quality feature of care-givers (Stiel et al., 2009). Stiel et al. (2009) support the idea of employing trained nurses and other team members for awareness of problems and deficits in the transition phase of patients from in- to outpatient care, resulting in increased quality for patients and care-givers. Currently, patient experiences and PS must be regarded as determinants of process quality in ASC (Erhart & Czihal, 2015). As aforementioned, the patient's point of view, as well as the knowledge possessed by patients about diagnosis and treatment, can be considered as outcome parameters for increased QOL (Harrison et al., 2009).

It is important to bear in mind that there is a relationship between doctor-patient communication and between inpatient and outpatient care (Keinki et al., 2016). Keinki et al. (2016) focused on patient-relevant endpoints such as PS, QOL, patient-centred needs and survival time to facilitate quality management certification processes. During quality management, in terms of certification, it is valuable to examine what improves patient-relevant outcomes. This can be done not only by

focusing on structure- and process parameters but also to show adaption to local treatment methods and patient-centred needs.

Care for cancer patients is so complex that it requires a multimodal approach. However, Fan, Burman, McDonell, and Fihn (2005) argue that this type of approach makes doctor-patient-communication more complicated. This research aims to identify the opportunities to create challenges that hinder quality improvement under ASC. Instruments to collect data such as QOL, PS, and QOC exist and can be used to identify gaps in the health care system. Results of outcome measurements of quality determinants among ASC are not yet available.

Two sources of material were used to assemble a literature review of articles about ASC: firstly, literature discussing QOL, PS, and QOC was consulted. Secondly, the traditional method of performing data searches in standard medical libraries was adopted. Furthermore, to ensure a comprehensive assessment of all criteria, other articles from nonmedical books and journals were consulted. This research aims to identify the features of the QOC in the new ASC model and to compare them with the QOC of the pre-existing health care model. This research evaluates patient perceptions of care under the new ASC healthcare model. It also considers whether QOL and PS impact patient health outcomes.

# 2.5 Summary of the literature review

This literature review introduced the concepts of QOL, PS, QOC and QM, evaluated the features of the new ASC health care model and identified gaps in the existing literature. Almost 40 years ago, Donabedian (1980) proposed that it is possible to evaluate the quality of health care by considering its structure-process-outcome elements. Health care quality measures use process measures for improving QOL, PS and QOC. Donabedian's (1980) work inspired researchers such as Aaronson et al. (1993) and Ware et al. (1995), who created questionnaires to evaluate the health status, social functioning and psychological wellbeing of the patients. In this research, Donabedian's (1980) approach is used to establish structured processes such as a specific time for decision making, doctor-patient-communication, patient-centred-communication and the recording of patient satisfaction and patient experiences during treatment processes. This research project identifies a new need for concrete quality of service that values patient views and perspectives.

Kleeberg et al. (2005) developed the PASQOC study, which is used to evaluate the needs and perceptions of patients undergoing cancer treatment. Although this study is of great importance, it also has weak elements that can be critiqued. For

example, it is reasonable to assert that written formulations about patient behaviour in questionnaires might not always represent the patient's true feelings. Another problem with this study is that it might not discriminate enough between a patient's satisfaction with the medical services provided and his or her satisfaction with the medical condition itself. In many studies, the patients express satisfaction with the care that they have received even though their medical prognoses are not good. An interview format would allow patients to speak more spontaneously and openly about their healthcare experiences.

The literature review revealed two further important authors, who focused on the outcome and measurements of satisfaction with care. Firstly, Blazeby (2001) reduced the heterogeneity to one cancer disease, considering not only "hard endpoints" of morbidity and overall survival data but also regarding the well-being and psycho-social function of these severely ill patients. Secondly, Velikova et al. (2008) performed an interesting study which combined questionnaires with interviews to create individualised assessment procedures.

Klindtworth et al. (2010) and Saunders, Lewis, and Thornhill (2011) suggested that semi-structured interviews are a good way of assessing patient well-being because they give the researcher the flexibility to ask additional questions not included in the original survey questions when appropriate. Reported PS would likely be much higher on a questionnaire than in an interview because patients might fear that their answers could bring about negative consequences when filling out a questionnaire. Kleeberg et al. (2008) argued that there is a significant correlation between the evaluation of PS during the interviews and the aspects of QOL in the questionnaires. There is a discontinuity between research results and daily practice, especially regarding necessary information about health status, gender, medical treatment and patients' needs and expectations.

The literature examined in this review mostly consists of standardised quantitative questionnaires. While valuable, these questionnaires should be augmented with assessments of quality parameters that patients can contribute to like the PASQOC questionnaire (Kleeberg et al., 2005). This idea is corroborated by Stiel et al. (2009), who argue that while studies examining cross-sectoral collaboration and interface issues between in- and outpatient care are rare, they could greatly affect patients' care. This study aims to assess the subjective experiences of patients and to ask patients directly about the impact of disease and treatment on their daily lives. The combination of semi-structured interviews with questionnaires will help to gain insight into the PS, QOL and, by extension, QOC of patients. The next chapter identifies the methodology that underlies this research and underlines its relevance.

# 3. Methodology

A methodology chapter explains in a philosophical manner how to conduct research. In this chapter, the researcher justifies her choice of methods by explaining why the chosen methods are useful and appropriate. Being important for the following research process, the term paradigm as a philosophical belief will be explained in detail. For this purpose, the paradigm refers to the tradition of post-positivism that equates to a qualitative approach, methodology refers to an observed and interpretative approach, and method refers to the approach to gather data and present results (McGregor & Murnane, 2010).

The methodology shows how research questions are expressed in the field and identifies research tools and the rationale for their selection (Oberst, 1984). In this research, a qualitative case study was identified as the best tool to answer the research questions. The current study is based on Yin's (2009) case study design. Qualitative research can enrich knowledge in health care when researchers want to ask, "How and Why" questions. In the health care system, patients and health care professionals focus on patients' needs and experiences as an interpretative process, in this case, a heterogeneous group of severely ill patients (Bowling, 1991; Greenhalgh & Meadows, 1999). Bowling and her colleagues argue that there are several practical and methodological difficulties which have so far reduced the use of patient-based information in everyday practice. This means that information about a patient's health-related QOL is valuable for doctors and could increase a patient's outcomes, but there is a lack of research looking at doctor-patient communication and health care decision-making from the patient's point of view.

The supply of treatment and services in oncology is complex and requires the cooperation of medical and nursing care. These professions come together to discuss further patient treatment and care processes. Hermes-Moll et al. (2016) state in their study that patient perceptions and preferences play a minor role for professionals in some cases and decisions are often made without considering comorbidity, conditions, or other individual aspects of patient lives. Taylor, Finnegan-John, and Green (2014) suggested in their study "No decision about me without me" meaning that patient-oriented medicine such as the patient-reported-outcome study (PRO) would lead to better QOL and a longer life for patients.

Taylor et al. (2014) explain that possible positive aspects (patients being informed and actively involved in the treatment process) provide indications that patients wish to be a part of the decision-making process and their medical outcome is

satisfied by therapy adherence and PS. Advanced care planning and shared-decision-making that involves the patients will require informed patients. Patient preference must therefore be presented in detail to caregivers and treating doctors.

It is important to recognise grief in patients (and their families) that are severely ill and to, in a professional manner, provide suffering patients (and their families) with hope and comfort. As Finestone, Hendrix, and Kelly (2008) stated, caregivers, family members and health care providers need to understand patients' perceptions of healthcare and their satisfaction with treatment. PS is an important outcome parameter that can facilitate continuity of care, increase patient compliance with treatment and improve quality interventions. The challenge is to obtain necessary information from patients; key questions must be identified that can elicit this information. With information about patient perceptions of healthcare, researchers can monitor the parameters of QOL and PS in everyday life using adequate questionnaires. For comparability, it is necessary to apply the same criteria to the same methods, e.g. regarding questionnaires for QOL and interviews for PS.

In this case, the SF-12 is an instrument for gathering QOL data. Validated instruments like questionnaires are commonly used in oncological practices, but relevant questions like individual patient perspectives are often missing. That is why the interviews were performed first, gathering data from the patients' points of view, which was then compared with the questionnaires. It is worthwhile to consider a lot of well-known influencing factors for the QOL. Influencing factors are socio-demographic factors (age, gender, culture), illness-specific variables (tumour state, conditions, medical parameters), psychological factors and duration of illness — the so-called "hard endpoints". However, there are areas of QOL that may not have been covered in research studies but may play an important role. Also, the value of dimensions of QOL is very individual but was not considered in this research project.

The topics dealt with in this research are complex and subjective. The researcher had to engage in a complex process to interpret the many factors that contribute to patient experiences of healthcare. The role played by subjectivity in this research is enhanced by the fact that qualitative research designs are not generalisable, and as Bearman et al. (2012) point out, different researchers can come to different conclusions when looking at the same thing. Bearman et al. (2012) argue in their research for the value of a qualitative approach to provide transparency and triangulation. The relationship between Bearman et al. (2012) and the researcher exists on the judgement-based qualitative design and the process for analysing qualitative data by thematic analysis with the key findings (thematic analysis).

ysis, in general, is an umbrella term for various processes of labelling text for understanding; more precisely describing key points from patient interview answers and finding code words for specific text sections). Also, Bearman et al. (2012) argue for this qualitative thematic analysis process as an inductive approach referring to a systematic qualitative manner of coding themes and then presenting them as values. A quantitative methodology did not apply to this research.

For validity purposes in this qualitative research project, the researcher used triangulation (Mays & Pope, 2000). The researcher focused on themes which she brought together for comparison. The method of triangulation is questioned by authors such as Silverman (2006), who sees triangulation as a reflexive analysis of the data collection rather than a proof for validity. The process of triangulation was used to question the reproducibility of the researcher's interpretation to clarify meaning. Considering that no perfect repeatability is achievable, triangulation is one way of using multiple perceptions of a patient's experiences (Flick, 2014; Mays & Pope, 2000; Silverman, 2004).

## 3.1 Introduction

This methodology chapter presents the research philosophies, research design and data collection procedures deemed most suitable for addressing this research topic. Based on a model developed by Yin (2009), this methodology chapter justifies the choice of a qualitative case study research design. Yin explains that case studies are iterative but straight processes with a single holistic design.

The researcher of this thesis relied on research which is referenced in sections on methodology, quality criteria and the debate around qualitative and quantitative approaches (Denzin & Lincoln, 2009; Jenkinson & al., 2002; Mays & Pope, 2000; Sale, Lohfeld, & Brazil, 2002). The researcher focused the literature review on studies that were relevant for answering the research problems. This search was limited to the results of 54 relevant articles, including keywords and methodological issues using a qualitative research design.

The overall purpose of this chapter is twofold. Firstly, the theoretical assumptions that underpin the research are introduced. Secondly, the researcher discusses whether the chosen qualitative inductive approach can be used with the research design of a case study and the method of semi-structured interviews and questionnaires. PS and QOL have been assessed in many quantitative inquiries; the qualitative studies that provide reasoning for these dimensions of QOL and PS and incorporate an understanding of patient behaviour are few and far between

(Bausewein et al., 2016). Bausewein et al. (2016) argue that patient-reported outcome measurements are well-known in palliative care. Individualised information that comes from the patient is valuable for clinicians and is essential for quality improvement and comparison with other practices.

This methodology chapter provides detailed information about how and why the evidence in this thesis was obtained. Following section 3.1 introduction, section 3.2 will present the philosophical ideologies that underpin this research. Section 3.3 will outline the research paradigm. In section 3.4, the research approach will be discussed. Section 3.5 will present a justification for the chosen research design. Section 3.6 summarises and discusses the application of this research. Finally, section 3.7 will present the ethical considerations that were respected throughout the research process.

# 3.2 Philosophical standpoint

This section explains how the study was carried out and describes its research strategy, design and methods. The researcher's aim in this section was to evaluate the appropriateness of the chosen methodology in terms of adequately answering research questions and contributing to the existing body of knowledge. McGregor and Murnane (2010) refer, when speaking of paradigms, to the philosophical beliefs of positivism and post-positivism. Positivism and post-positivism are two basic paradigms which comprise world-views from philosophical and technical assumptions. McGregor and Murnane (2010) also speak of four principles of methodology when defining paradigms. The four principles or axioms come from Greek philosophy and mean "to deem worthy": epistemology, ontology, logic and axiology. Epistemology asks questions such as How do people come to knowledge? Ontology considers topics to do with existence, being and reality and poses questions such as "What count as acceptable arguments?" Logic addresses accuracy and implication in the development of opinions or insights. Axiology has to do with moral and ethical decisions, especially the role of participants and researchers in study processes. Axiology is of interest in this study because it relates to the emotions, hopes, values and perceptions (of patients). These axioms from Greek philosophy are stated as true and are therefore taken as a starting point in the research process.

This research considers the constructivist methodology approach as a starting point in qualitative research. Denzin and Lincoln (2009) stated that qualitative research is not based on one single discipline or methodology. It is necessary to explain the terms of the two different paradigms, realism and constructivism because of their multifaceted nature. What this means is there are various forms

and faces of, e.g. constructivism such as: feminist constructivism, radical constructivism, social constructivism. Oulasvirta, Tamminen, and Höök (2005) devoted their research to discussing the approaches of realism and constructivism. The roots of realism lie in natural science, whereas constructivism is based on human and social science. Realism is structured and seeks to uncover "truths" in an ontology. Constructivism, on the other hand, allows multiple interpretations and its ontology is socially constructed. The constructivist paradigm applies to this research project because it is well-suited to evaluating the human emotions expressed in the patient interviews. This study, which qualitatively combines semistructured interviews with questionnaires, can be seen as a pilot model in health care. The research is based on the idea that some problems in social situations cannot be satisfactorily resolved with the use of only one research technique or research tradition.

The term "understanding" in sociology can be traced back to Weber (1978), who viewed social action as an interpretative process. He stated that qualitative research depends on understanding the actions and experiences of the participants in a study. It is necessary to observe the research subject in order to gain knowledge about his or her subjective points of view and to show how qualitative research methods enrich knowledge in health care (Mays & Pope, 2000).

This methodology chapter seeks, on the one hand, to demonstrate how qualitative methods can provide a description and understanding of a given situation, attitude or behaviour. On the other hand, the chapter explores how successful triangulation is part of the validation process used to compare results. Sale et al. (2002) declared that qualitative and quantitative methods do not study the same phenomena because they have different paradigms. Triangulation is, therefore, problematic. They argued that many studies combine the two paradigms in health care research, but the social experiences and interactions of patients are not looked upon in quantitative methods. Sale et al. (2002) expressed that the two paradigms cannot study qualitative and quantitative methods in one but can be combined for complementary purposes. Sale et al. (2002) also stated that all research is based on the fundamental tenets of positivism but can be divided into two groups: positivism and the positivism-interpretivism paradigmatic approach. This research does not follow the positivistic approach, but rather qualitatively combines elements of two different methods, as proposed by Denzin and Lincoln (2009).

As Daly et al. (2007) stated, combining methods in different research settings creates a broader picture and helps researchers gain access to new levels of knowledge. Daly et al. (2007) stated that research design and ethical considerations must closely match the research questions in a qualitative interview study.

Daly et al. (2007) developed the model of a hierarchy triangle with different levels (level I-IV) of evidence for practice in qualitative research. Using methods in a lower area of the hierarchy can be appropriate for doing research. The study type of a single case study of level IV can provide insights on the views or experiences of one person. The researcher will pursue and develop this approach. The ascending hierarchy from descriptive study types of level III, conceptual studies of level II and the generalisable research study of level I define the essential features for a qualitative research study.

Level IV of the triangle should be especially considered in a single case study and will be in line with this research methodology. Such studies produce data from previously unexplored contexts with interviews, e.g. with one or a small number of patients and can signal the existence of unusual experience. A limitation of such case studies is that the results are not generalisable. They can, however, raise topics that can be examined in further studies.

The researcher in this inquiry does not advocate the replacement of quantitative with qualitative research but rather suggests that different paradigms be combined with balancing one another out (Silverman, 2004). The theoretical paradigms and the characteristics of epistemology, ontology and methods are discussed in the following paragraph. The research questions influenced the choice of research strategy as well as the methods used for data collection and analysis.

# 3.3 Research paradigm

## The philosophical paradigms in social research

The term ontology originally referred to the theory of being, of focusing on the beliefs of the real world. This is a starting point for the philosophical position of the researcher and is based on the schools of thought divided into realism and relativism. Realism is based on the acceptance of facts in the real "objective" independent world; relativism accepts that reality is only subjective (McGregor & Murnane, 2010). The term epistemology refers to the meaning of knowledge as seen by the researcher, whether objectively or subjectively. Two important implications from an epistemological position are the paradigm of positivism and that of constructivism. These terms must be explained to clarify the researcher's philosophical position (Easterby-Smith, Thorpe, & Jackson, 2012; Oulasvirta et al., 2005).

The qualitative method has been hailed as a new approach for evaluating the quality of care in the health care setting. It is a suitable method for understanding outpatients' views, needs and expectations in the specialised area of health care

supply (Bowling, 1991; Greenhalgh & Meadows, 1999; Taylor et al., 2014). Kemppainen (2000), for example, conducted patient interviews to learn more about patients' behaviour during interactions with members of staff. The central principles of qualitative research revolve around carrying out an in-depth analysis of subjective motives, behaviour and attitudes (Kvale & Brinkmann, 2009).

This research aims to identify attitudes, motives and behaviour associated with the decision-making around important health care issues. Personal attitudes can, as Patton (2002) states, be used to define psychological-, physical-, social-, and interpersonal well-being. Personal attitudes and environmental factors influence patient perceptions of QOL and PS (Kleeberg et al., 2005). As Kvale and Brinkmann (2009) point out, data from interviews could be used to interpret information about patients' needs and expectations. From the researcher's point of view, a questionnaire alone cannot adequately describe a patient's emotions, attitudes or physical and psychosocial condition.

It is necessary to define an appropriate research paradigm because of these different philosophical approaches which imply different ways to find a solution for a theoretical problem (Bryman, 2008). When choosing a research design, it is helpful for the researcher to choose that which most appropriately answers the research questions.

#### 3.3.1 Social constructivism

This research design, as proposed by Yin (2013); (Yin, 2009) consists of a case study and is based on a constructivist paradigm. The roots of constructivism lie in the human and social sciences (Oulasvirta et al., 2005). As Oulasvirta et al. (2005) point out, the advantage of this approach is that it enables participants to present their personal views about reality while sharing their stories and feelings. This helps the researcher to understand and interpret these understandings of the participants' actions.

Yin (2009) believed that in all research, validity and reliability must be established. More specifically, from a positivist perspective, the validity of data is equivalent and repeatable. Murzi (2007) and Given (2008) stated that research from the positivist stance believes that there is only one objective reality constructed of an appropriate hypothesis and facts. Post-positivists, on the other hand, accept multiple truths. In the case of the post-positivists, therefore, validity and reliability are subjective. That said, all methods must be systematic and well documented to establish dependability. Constructivists and critical realists are two trends in post-positivism epistemology. It is interesting to note that, as Blanche, Blanche,

Durrheim, and Painter (2006) explained, the quantitative constructivist paradigm can also be found in qualitative paradigms when one recognises that observations are constructed and therefore reality is imperfect. Based on the assumption that reality is a social construction, the constructivist paradigm rejects absolute truth. A constructivist or interpretivist typically uses a qualitative methodology (see TABLE 52: Major philosophical paradigms in social research (based on Guba & Lincoln).

Paradigm	Positivism	Post-positivism	Critical Theory	Interpretivist/ constructivist
Ontology	Hidden rules, "real" reality	Imperfect "real" reality	Reality is not real and performed by society	Reality is created by individuals in groups
Epistemology	Reliable and valid tools as quality criteria	Critical tradition and findings can be true	Subjectivist	Meanings and perceptions of human beings, Events and activities
Methodology	Verification of hypotheses	Falsification of hypotheses,		
Method	Quantitative What works?	Experimental, qualitative	How can I change this?	Qualitative, How and Why

The researcher discussed methodological approaches, which justify the later chosen research method, through qualitative research that advocates the constructivist position. The classical research paradigm of a qualitative social constructivist format is the most suitable paradigm to answer the posed research questions. The researcher depended on her personal views and knowledge to determine her research design and how best to answer the research questions. A constructivist interpretative approach is most appropriate for this research because it allows the researcher to understand the patient's experiences of the outpatient setting. An example of the so-called interpretive approach is "understanding" (Habermas, 1984; Weber, 1978). Qualitative research generates an understanding of the meaning and events of the participants as an important focus of the theory (Maxwell, 2012). "Understanding" is the exact opposite of a

positivist approach, in which testable hypotheses and statistical numbers are the focus. The researcher in the current research would expand the components of influencing factors by resources, skills, setting— the so-called environmental factors.

# 3.4 Research approach

Asking questions about why patients behave in distinctive ways and focusing on patients' perceptions, opinions and experiences using a qualitative approach creates considerable disagreement between researchers in the health care sector regarding how to reliably evaluate the collected data (Bowling, 1991; Greenhalgh & Meadows, 1999). For example, in quantitative research, a patient's "concordance" agreement can be measured by how many patients are concordant or not with a given treatment. But, in qualitative research, the aim is to explore why and what happens, and this underlines the need to find a suitable solution for this issue. The researcher tried to find a degree of agreement which she called concordant valuation for a category or grading technique. The purpose is for later use of comparison of different valuations of attributes. In quantitative research, measuring without error is the so-called "gold standard", but the researcher attempts to find a technique which is less stressful and burdensome for patients and can be quickly carried out (Baumann et al., 2012). It was not relevant to note whether patients gave "good" or "bad" assessments of the care provided in the outpatient unit. Instead, it was essential to consider how closely patient answers corresponded to the list of nodes as well as how important specific nodes and questions were for an overall assessment of QOC.

A qualitative approach was selected for the research design because, in qualitative studies, the main goal is to gain an in-depth understanding of relationships and participant perspectives from a subjective point of view (Flick, 2014). This research adopts a social constructivist rather than positivistic approach because, as Maxwell (2012) states, philosophical assumptions allow one to have different perspectives on the nature of reality. Contextual factors such as ethical standards, participant concerns, and experiences, and data and conclusions could all influence the research design or the validity of the study.

Fitzpatrick et al. (2006) argue that, in reality, numerical scales may measure something entirely different to reveal a problem. The realisation of a message depends on the person who interpreted the scales and the context in which the message is received. The interpretation of a message is not wide-ranging enough to provide the subjective aspects of a patient's experience. Subjective experiences, such as psychological symptoms or pain, provide insights into a

patient's day-to-day life. However, in making these statements, Fitzpatrick et al. (2006) consider that all data need to be presented without bias. That said, Aaronson et al. (1993) point out that at each stage of the research process, bias can be found. Bearman et al. (2012) argue that in multiple randomised, controlled quantitative trials with large samples of patients, the effect of bias is balanced out unlike qualitative studies that are neither generalisable nor without bias.

This research does not aspire to be generalisable, but rather to reflect the diversity in each group of patients. Therefore, the researcher included questions about physical, psychosocial and organisational processes that played a role for patients during their cancer treatment. Transcripts and notes are the raw data and provide a detailed record but cannot provide explanations. For this reason, the researcher focused on themes which she brought together for comparison. The researcher has to make sense of the data. Therefore, she employed the constant comparative method, as suggested by Goodrick (2014) in order to compare findings and interpret the gathered data. This approach enabled the researcher to answer her research questions from different perspectives. The group of participants in the study was selected purposely, but the group of patients was not used for interpreting the collected data. The method of triangulation was also used in this research to address the issues of rigour and validity in qualitative research (Morse, 1991). The information from the collected data from different methods delivered findings which can provide certainty and confirmation. In the following chapter, the researcher justifies her chosen research methods by citing Blaikie (2009), who argues that in social studies, tools and methods are bonded together because the method is almost the tool.

# 3.4.1 Considerations of qualitative research in social science

Data can be gathered in many different forms and can be described either with words, such as in diaries and interviews, or with numbers, such as in statistics (Blaikie, 2009). Research methods such as questionnaires or observations can represent data both in numeric and verbal forms (Creswell, 2013). However, it should be noted that a quantitative approach provides more generalisable results and lesser sensitivity regarding the dissimulation of information.

One of the advantages of the qualitative approach is the close collaboration between researcher and participant. While enabling participants to tell their stories, qualitative researchers uncover complex and causal relationships as well as aspects that are often difficult to measure (Crabtree & Miller, 1999). Participants can describe their views of reality, which enables the researcher to understand patient experiences better. Data about the quality of oncological treatment and the quality of the patient experience was gathered in this research project to

evaluate the extent to which the new ASC model is profitable for the patients. From this point of view, the classical research paradigm of a qualitative social constructivist format is the most suitable paradigm for the research.

#### 3.4.1.1 Decision of interview types and design

In empirical social research, qualitative interviews and questionnaires are key because they initiate a specialised conversation between interviewer and interviewee (Tellis, 1997). The background of this study's methodology is data generation based on the paradigm of social constructivism: human beings communicate. By way of a qualitative interview, a researcher can gain knowledge about emotions, thoughts, biographies and experiences (Flick, 2014).

This qualitative inquiry is exploratory. As Yin (2013) stated, an exploratory case study is the starting point for doing social research and is often used in causal investigations. In an exploratory case study, the researcher considers not only the perspectives of the participants but also how the participants interact with the social groups around them. Depending on factors such as research aims, questions, and participants, several different methods can be employed in a case study. Kvale and Brinkmann (2009) suggested that the answers obtained in qualitative interview studies depend on the topic and the purpose of the investigation. It is up to a researcher's discretion to develop an interview technique that most efficiently and ethically obtains the desired data from the interviewees (in this case, severely ill cancer patients).

The case study design adopted in this research had an explorative goal. Each form of generated data was corroborated with methodological triangulation, which revealed contradictions, similarities or differences that the researcher reflected upon. The study type, especially of a case study, in general, generates rich sources of data and provides access to information such as how people build identities and opinions and how participants reflect on the past. An interviewer can glean analytic insights by understanding a patient's experiences.

#### 3.4.1.2 Development of the interview questions

The sample in the case study consisted of a total of twenty patients, all of whom suffered from advanced GI cancer and were being treated at the same outpatient unit. Every patient fulfilled the requirements of the ASC model which were: 1) has a severe oncological illness of a gastrointestinal tumour disease; 2) is being treated under chemotherapy; 3) has had a consultation in cooperation with all involved parties such as doctors, nurses and team members of health professionals. Minimum age of 18 and above was specified.

In addition to the attributes of general health, symptom burden, physical, social, and role functioning, the interview also generated social demographic data. Data relating to age, gender, marital status, profession, and driving distance from the practice is valuable but did not play a primary role in the questioning. These demographics were only collected to show that there were no significant deviations between the individual patients' data. This research did not form a comparison based on the demographic data of participants. Patient groupings based on factors such as gender, age or type of tumour would have been too small to result in any relevant comparison.

The fifteen interview questions referenced all keywords (PS, QOL, QOC, QM, ASC) as well as the most important patient-identified quality of life attributes, including physical, psychological and interpersonal well-being in relation to the content of Padilla, Mishel, and Grant (1992) and Kleeberg et al. (2005). The combination of these attributes formed the basis for the interview questions that followed (see Table 15-17 p. 146). Kvale and Brinkmann (2009) outlined the eight stages of an interview, which were considered during the development of the interview questions:

<u>Thematising</u>: The consultation of pertinent literature giving rise to possible interview questions and themes.

<u>Planning</u>: Based on the PASQOC study (Kleeberg et al., 2005), the interview questions for the investigation concerning "why, what and how" elements of the thematic focus.

<u>Interviewing</u>: A detailed, self-developed guide for individual face-to-face interviews. Each interview lasted between 20-35 minutes and was tape-recorded. Unlike Rubin, Pronovost, and Diette (2001) who conducted a study using an open interview in health care, an iterative design was not used in this case. The questions were semi-structured, which means that instead of using a flexible design, an interview guide was used to ask questions with open-ended questions, and the participants talked freely.

<u>Transcribing</u>: The high-quality oral audiotape recordings transcribed to written form.

<u>Analysing</u>: Twenty interviews categorised. Ten interviews were conducted with patients being cared for under the existing health care model, and ten interviews were conducted with patients undergoing care under the new model of ASC. All interviews were structured by the three main thematic blocks (interpersonal, medical and organisational) and were individually graded (see section 4.3).

<u>Verifying</u>: Specific questions altered after a pilot interview that was conducted to determine the validity and reliability of interview findings. Reliability, in this case,

refers to the consistency of findings. Validity means that the study investigated what was intended to be investigated.

<u>Reporting</u>: All results of the interview reported scientifically; informed consent was provided, and ethical aspects were considered (see section 3.7 Research ethics and data protection).

An awareness of how to correctly word questions and the flexibility to adapt questions based on the situation at hand is important for a researcher. A problematic interview situation can arise if a patient becomes emotional. In this study, the interviewer could direct the interview using targeted questions. This means that the interviewer mentioned several topic areas and the participant could answer freely and choose which topic they wanted to answer or not. As mentioned in Table 7, the researcher considered different interview types as well as standardised and semi-structured interview definitions. Flick (2014) compiled a comparison of interview types and the differences between them:

TABLE 7: COMPARISON OF DIFFERENT INTERVIEW TYPES ACCORDING TO FLICK (2014)

Criteria	Standardized Interview	Semi- structured Interview	Expert Interview	Narrative Interview	Problem centred interview
Openness to the issue	Focused on standardized questions	Focused on open questions	Focused on the expert less interest on the interviewees	Focused on participants to ask and remember their experiences in the context of biographical research	Focused on biographies of different groups of people
Structuring of the issue	Guidelined questionnaire	The interview guide mentions several topic areas and participants can answer freely	Using semi- structured interview guides	Narrative questions generated	Interview guide as basis and narrative interview
Domain of application	Hypotheses	Not hypothesis confirming	Knowledge of expert from the institution	Biographical courses	Group discussion
Problems carrying out the method	Missing the personal point of view of participants	Interpretative not for biographical processes suitable	Only special knowledge of the expert and how to find the right expert	Time consuming narrators given much time to tell their stories, cultural problems of narration	Only subjective viewpoints linked to qualitative content analysis
Limitations	Summary of objective features, only data measuring aspects	Biased by the interviewer and interviewee	Representing a group not a single case. Definition of expert is unclear	Only reduced of narrative experience of participants	Includes group discussions and biographical method as a second and additional step

A semi-structured interview is used when the researcher would like to interview someone and has a list of questions that cover the topics in a particular order. In this research, the following approach is used for the interviewing: The interview guide provides a set of precise instructions (see table 58: Interview guide German-English; in chapter 11, Appendix C: Method). The researcher offered the opportunity to discuss several topics and the participants were given the chance to answer freely (see section data analysis methods 4.4.1.1). The researcher of this project decided on an interview structure that involved single face- to face interviews

rather than focus group discussions. Given the emotional nature of the research topic, it would have been difficult trying to discuss personal, individual questions in a group setting (Pascal et al., 2011). In contrast to this open format, the focus in standardised interviews lies on predefined, fixed "standardised" questions, and it is not possible to learn the personal points of view of the participants. Standardised questions, unlike open-ended questions, do not offer the respondents the chance to voice other opinions, feelings, or attitudes. An advantage of open-ended questions is that participants have the chance to explain if they did not understand or do not have an opinion on questions. That said, open-ended questions in semi-structured interviews are sometimes too time-consuming, and the interpretation and analysis of the data more complicated (Spiroch, Walsh, Mazanec, & Nelson, 2000). That said, the researcher chose the in-depth semi-structured interviews because that encourages respondents to communicate their beliefs and values that are so central to this method and gain a rich understanding of the topic of interest.

The researcher justifies using interviews in this qualitative research because they provide information about patient perceptions and needs from the patient's point of view. The advantages of the interview procedure are the intimate personal atmosphere and the interviewer's knowledge about the health and living conditions of the interviewees. The interview could be terminated at any time, and a consultation and support appointment could be scheduled with the doctor if necessary. The interview also has its potential disadvantages. The process requires time and a skilled and carefully trained interviewer is required. The lack of anonymity resulting from a face-to-face interview could have biased the answers of the respondents. Interpretation, as it may vary from one researcher to another, is subjective. Qualitative research is primarily subjective because it is the process of meaning and meaning-making given through the interaction between researcher and participant. An interview guide for the semi-structured interviews was developed to avoid bias (see section 1.5 Influencing factors, 3.7 Ethics and 6.1.3 Limitations and opportunities).

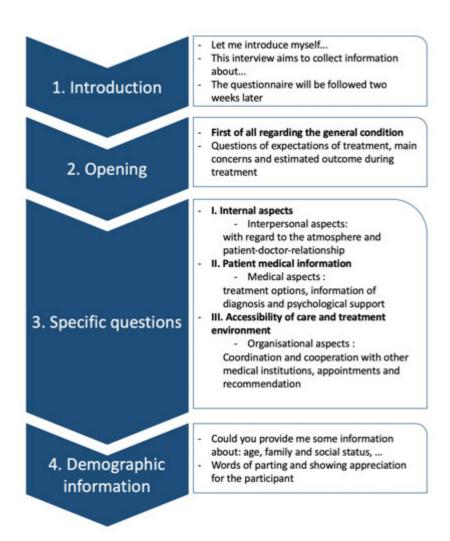
#### 3.4.1.3 Development of the interview guide

A semi-structured interview requires a guideline that dictates what questions can be asked. The questions included in the guideline for the interview used in this research were very similar in content to those asked in the questionnaire. As Carr, Gibson, and Robinson (2001) argued, it is important to emphasise the underlying processes of change and the expectations of the patients during their treatment. Carr et al. (2001) emphasise that QOL is an individual construct and that most questionnaires cannot perform patient-centred measurements because every patient has a different perspective regarding particular individual belonging in their

lives. Carr and Higginson (2001) demand individualised measures for health-related QOL, e.g. simplifying testing systems and using short interviews that seek to gather targeted, patient-centred information. Carr and Higginson (2001)'s ideas are particularly relevant to the research performed in this thesis, which aims to assess health-related QOL by collecting information about the expectations and experiences of patients throughout their illnesses. The questions in the interview were arranged in sequential order, but the interviewer was given free range to diverge from that order. The interviewee could answer freely and in his or her own words

The four elements of the interview guide are pictured below in FIGURE 8: Overview of the Interview guide.

FIGURE 8: OVERVIEW OF THE INTERVIEW GUIDE



For reviewing and verifying the content of the interview questions, a preliminary test was conducted. This was to help reduce the risk that the patients would not answer the questions appropriately. The spontaneous nature of the participants' answers meant that there was much information to compare in both study groups.

Pre-tests are used to screen an interview, ensuring a logical order as well as validity and reliability verification (Byrne, Griffin, Blazeby, Conroy, & Efficace, 2007). The tests improve quality and significance. The following factors were reviewed during the pre-test conducted in this research:

- The duration of the interview
- Understanding of the questions
- Interest and openness of the patient towards the questions
- Redundancy-free
- Impacts and completeness of the interview questions

#### 3.4.2 Considerations of quantitative research in social science

Doing quantitative research requires using mathematical, statistical and numerical data to provide generalisable findings which test a hypothesis in a large sample size with standardised measures and a deductive approach (Robson, 1993; Saunders et al., 2011). Trochim (2006) argues that all quantitative data is based on qualitative judgement; however, all qualitative data can be explained numerically, e.g. by the allocation of values.

#### 3.4.2.1. Instruments for quantitative research

In oncology, questionnaires are one of the traditional data generation methods designed to obtain information about the quality of life from a larger group of patients (Bullinger, Kirchberger, & Ware, 1995). Patients in oncology fill in standardised questionnaires several times during their treatment processes. Central to a questionnaire in oncology is a standardised collection of questions about the state of health, every-day functionality, pain, physical and psychological well-being and illness-specific items about treatment (McHorney, Ware, Lu, & Sherbourne, 1994). One reason for using questionnaires is that they are popular and easy both for researchers and participants to understand (Young, Walsh, Butow, Solomon, & Shaw, 2011). Apart from the time consumed when patients fill out the surveys, such questionnaires usually involve low costs. Young et al. (2011) state that questionnaires are a manageable and straightforward approach to obtain a current impression of the values and attitudes of participants. As instruments, questionnaires demonstrate consistency and robustness. A standardised questionnaire was therefore deemed to be an appropriate add-on to the interview in this research.

A discussion of qualitative and quantitative research design issues and how design decisions can impact qualitative data analysis.

From the philosophical stance, the positivist methodology is interested in explaining relationships to formulate laws and predict generalisations. Post-positivists, on the other hand, seek to understand causal relationships with a qualitative approach. A post-positivistic stance is often used to gain insight into patient perspectives (Creswell, Klassen, Plano Clark, & Smith, 2011). In this thesis, the philosophical stance of social constructivism was selected because this provides information about patient perceptions and experiences from the patient's point of view.

The constructivist approach is based on understanding the world of human beings and how they interact (Davidson & Mills, 2005). More explicitly, constructivist researchers establish a reliable means of communication with participants to achieve understanding about human perceptions. Both qualitative and quantitative research methods may be used in support of qualitative data (Creswell et al., 2011). Creswell et al. (2011) point out that interviews are often used as a data collection method in constructivist research. This means that the constructivist researcher tends to rely on patients' points of view. In this thesis, the researcher worked with the study participants daily. She mitigated possible bias resulting from this by limiting discussion in the interviews to the 15 predefined study questions.

This type of qualitative data generation can lead to bias in the form of transference or countertransference. Because of this, the researcher strived to minimise the number of interactions between the interviewer and interviewees. The interviewer refrained from commenting or reacting to patient answers in any way and ensured that conversation was limited to the predefined questions presented in the semi-structured interview. The researcher was aware that comments made by severely ill patients in the context of the semi-structured interview were likely influenced by social interactions between the treating doctor and team, personal social standing and family situation, and individual experiences with the health care sector. The researcher in this study was aware that patient communications about treatment and experience with the medical system were influenced by the progression of the patients' diseases. The perspectives expressed by patients provided insight into a specific moment in time at a particular medical outpatient unit. A similar research project with different patients in another country might have produced different results. The ability to identify how patients experience medical treatment in any given outpatient unit at any given point in time is one of the central research aims of this study. Hence, social constructivism is the approach the researcher chose, because the interpretive framework enables the researcher to seek understanding of the participants' lived experiences and perceptions and the development of their particular meanings that correspond to their expertise (Creswell, 2013).

In this thesis, the data used to evaluate QOC pertains to medical decisions and treatment as well as interactions between the treating medical team and patients. Different approaches are used when conducting an interview, formulating questions and deciding how much time should be given to interviewees when answering questions (Mays & Pope, 2000). As mentioned before, Mays and Pope stated it is necessary to observe the participants to gain understanding about their subjective standpoints and to show how a qualitative research method can gain new knowledge.

On the issue of social constructivism, Weber (1978) stated that social action is an interpretative process and that qualitative research depends on understanding the actions and experiences of the participants in a study. As mentioned before, social constructivism is a joint venture between researcher and participant. Noteworthy is the information on the views of patients about their expectations and perceptions under treatment.

Roller and Lavrakas (2015) point to the constructivist view as the so-called reality and a product of our own experience and personal views and, as a result, the relationship and perception one has about these experiences. Perceptions and opinions of experiences from human beings must always be seen from the background of all our previous experiences and the resulting values and attitudes. These considerations of perceptions and experiences of the patients contributed to the idea of social constructivism. A social constructivist orientation does not aim for the notion of truth and objectivity (Roller & Lavrakas, 2015). Beyond this, social constructivism aims to consider the multidimensionality of perspectives and points of view that enrich our understanding and lead us to new positives outcomes. The researcher under social constructivism considers the difficulties of human experiences and the different aspects of life that are intertwined and mutually influenced. The conditions of medical care and the perception of the QOC are social constructs of society.

Social constructivism aims to design research that leads to useful outcomes. By this, a qualitative research design should also lead to credible, analysable and transparent results that are transferable for further research. Social constructivism and qualitative research walk together and need each other. As mentioned by Roller and Lavrakas (2015), essential for social constructivism are distinctive qualities of qualitative research such as the importance of context and meaning, researcher as an instrument, participant-researcher-relationship, the flexibility of the research design, and the messy analysis and inductive approach.

In this research, attributes of quality are considered through an in-depth interview. The researcher considered bias and the impact of the participant-researcher-relationship and the potential bias of transference and countertransference. The connection of the researcher and participants and the subject difficulties place the researcher at the centre of the data collecting stage. Truly, the researcher with his or her experiences and skills is the tool by which information is collected. The closeness of the participant-researcher-relationship and the observed subject is the core of the in-depth interviews and provides deep understanding. If the data are collected and interpreted objectively and in an unbiased way, a useful interpretation of the outcomes can be achieved.

A specific point in this research design is flexibility (see Roller and Lavrakas (2015)). During the semi-structured interviews, the researcher allows the interviewee flexibility in answering the 15 predefined research questions in turn. Consequently, to offer flexibility during the interview process, in some cases, answers resulted in inconsistent, monosyllabic or thematically different answers from patients. Roller stated this as the so-called messy analysis. The researcher follows Roller's approach to analysing the outcomes from inside out of this qualitative research, getting meaning from the data by way of the data itself. Therefore, as a social constructivist, the researcher describes the aspects of the QOC entirely with 31 different thematic nodes. The researcher focussed on organisational, medical and interpersonal aspects of care in the process of data generation. All answers were allocated to these 31 nodes and valued with numbers (-3 up to +3). The numerical value of the allocation and alignment of the answers regarding the thematic nodes opens the opportunity for in-depth analysis through triangulation and constant comparison to find out the valid and reproducible key themes to determine the QOC in both groups with and without ASC. These determined key themes address what is especially crucial for oncological patients.

The researcher's profound personal and professional experience is necessary to understand the interview answers of the seriously-ill patients in the context of their oncological treatment situation. However, the researcher is aware that there is a risk of transference and countertransference. Objectivity was supported through the differentiated thematic allocation of interview answers and nodes to mitigate the bias. As an alternative scenario, the researcher has had the opportunity to interpret every single interview. She concluded that only through a comparison of interpretations from 20 different interviews with numerical validation and sorting, can relevant and valid key themes of the QOC be worked out and evaluated.

One issue of this work is to clarify how a reduction of interviews to numbers can lead to a deeper understanding of experiences and points of view of these severely-ill patients to evaluate the QOC. The consecutive steps of the analytic process will be described in detail in the summary of the data analysis section (chapter 4 Methods). In the discussion and conclusion chapter, the researcher will interpret and evaluate the findings of the in-depth-analysis, based on her experience and expertise, to gain new knowledge that is applicable and reproducible in further research.

## 3.4.2.2 Questionnaire design

Important elements in any questionnaire are the interviewee, the questionnaire and the potential biases or influences imposed by the interviewer or setting on the interviewees (Bryman, 2008).

#### Generic- and disease-specific measurements

Generic measures can be used with all members of the general population, and individualised measures measure a health-related concept within a specific disease group. A potentially useful questionnaire can be identified by way of a literature review or based on recommendations from researchers and professionals. The following paragraphs consider various generic questionnaires and explain whether or not these questionnaires were deemed to be appropriate for this research.

It is important to clarify the difference between generic and disease-specific questionnaires. Stewart, Teno, Patrick, and Lynn (1999) stated that in cancer research, both generic and disease-specific measures are commonly used. A generic health assessment can be applied to many different diseases and does not focus on specific effects and outcomes of disease. Others argue that the outcome is a threefold construct. Different endpoints that are weighted based on illnessspecific factors reflect the individual needs and expectations of patients (Hammermeister, Shroyer, Sethi, & Grover, 1995). A disease-specific assessment measures "hard endpoints" of important changes in health and focuses uniquely on one specific illness (Stewart et al., 1999). Hard endpoints are objective and reliable facts such as clinical tumour markers. Hard endpoints can show that a complex system is out of balance, but they cannot explain pathologic complexities or unexpected events without the aid of other, often qualitative perspectives. Frommer (1998) suggested that in individual or small group interviews, interviewees have the opportunity to answer more explicitly and individually than in questionnaires.

For economic validation, the EuroQol (EQ-5D) utility measurement was developed (Garratt et al., 2002). This standardised non-disease-specific questionnaire includes quality of life measures to 14 different health states. The data generation was carried out with a visual analogue scale like a thermometer. The EQ-5D is inappropriate for this thesis because it addresses topics that are not relevant to this study, such as general activities, depressiveness, pain, self-supply, and mobility.

Two of the best-known disease-specific measures are the Sickness Impact Profile (SIP 10 items) (Bergner, Bobbitt, Carter, & Gilson, 1981), and the Karnofsky Performance Status Scale (KPS 6 items) (Van Knippenberg & De Haes, 1988). The quantitative SIP 10 questionnaire focused on health status to identify changes and relationships that occur between groups of patients with different diseases. The SIP is not relevant to this thesis because it does not generate data of severely ill patients. The KPS is scored only by a physician and calculates percentages of the functional health status of individual patients. When working with patients, practitioners need a way to rapidly classify condition-specific symptoms as well as a patient's functional status (Patrick & Deyo, 1989). This assessment instrument cannot evaluate the QOL of cancer patients. For this reason, it was disregarded in this thesis.

Other specific instruments are the Functional Assessment of Cancer Therapy (FACT) questionnaire (Cella & Stone, 2015) and the Quality of life Index (QLI) for cancer patients (Daig & Lehmann, 2007). These questionnaires generate data on disease-specific (in this case, oncological) QOL. Neither of these two questionnaires is well suited to this research project. The quality of life indicator is not compatible with the research questions posed in this thesis because it focuses on external assessments such as hard endpoints. FACT is a health-related multi-dimensional questionnaire with 25 items. This questionnaire contains tumour specific modules, e.g. anaemia, fatigue. Key elements of this questionnaire are inappropriate for this research project because the topics covered do not correlate with the subject matter addressed in the interviews and have nothing to do with psychometric quality.

The standardised questionnaire, for example the SF-36, is a tool that provides a generic assessment of how treatment affects the quality of life in patients. It collects data regarding attributes of pain as well as physical and psychological well-being (Kleeberg et al., 2008; McHorney et al., 1994; Morfeld & Bullinger, 2008). However, as McHorney et al. (1994) explained, the SF-36 questionnaire is time-consuming and burdensome for seriously ill patients to complete. For this reason, this research elected to use a shorter form survey analogous to the SF-12, which can be completed in 15 minutes. The SF-12 is an objective tool used as a standard-ised questionnaire in extensive quantitative studies.

Generic- and disease-specific measurements sometimes overlap, e.g. pain and special functional status. As mentioned, the preference for one or the other (disease-specific or generic measurements) depends on methodological and practical restrictions. In this research, the generic assessment was chosen because the study was comparative. Generic assessments allow a researcher to compare the outcomes of an intervention rather than investigate a medical treatment or the special status of a diagnostic group. The researcher has no interest in important disease-specific changes regarding the health status of the participants. Instead, she is interested in recording data on subjective feelings and the so-called attributes of the well-being of patients undergoing cancer therapy.

Bowling (1991) explains that the transferral from different measurements of generic and disease-specific quality of life depends on the physician's perceptions of the personal subjective feelings of the patients. Gill and Feinstein (1994) argued in favour of augmenting the standardised questionnaire with an additional instrument such as an interview assessment to incorporate the patient's experience. The researcher adopted this technique. This thesis paid specific attention to the conceptual differences and comparisons between QOL and PS.

# Health-related quality of life tools

Health-related quality of life tools have the potential to identify specific and general health needs of patients (Asadi-Lari, Tamburini, & Gray, 2004). TABLE 53: Comparison of different questionnaire types generic and disease-specific in Appendix B: Methodology, presents the different generic and disease-specific questionnaire types, outlining their advantages and disadvantages for application in this research.

Generic measurements, as Coons, Rao, Keininger, and Hays (2000) explain, are an essential element of healthcare evaluation. Hundreds of generic assessment instruments have been developed. The researcher reviewed the most commonly used SF-36 (and the shorter SF-12) questionnaires to determine whether they were suitable for her research project. She required that the questionnaire has a conceptual framework, not be burdensome for the patients, be easy for the patients to fill out and have language adaptions. The SF-12 survey fulfilled these requirements and was well-suited to providing data that would answer the research questions. The conceptual model of the SF-12 combined three item categories (pain, physical, and psychological aspects). These three categories are very applicable to the topic of the research. It was important for the researcher to quickly receive condition or treatment-related information that had to do with health-related quality of life. The background of the shorter form of survey is the SF-36, which was developed from the RAND Corporation (Ware & Sherbourne, 1992).

The self-administered SF-36 covers eight health concept items such as physical functioning, pain, mental and psychological health, emotional issues and supports the notion of "positive health" (Coons et al., 2000). The decision to use generic or disease-specific depends not on "good or bad criteria" but is driven by the purpose of objectives. In this research, the objectives are: How can we evaluate PS and QOL qualitatively and are they suitable for the evaluation of QOC? Are there differences in the QOC provided by the new ASC model as compared to the previous oncological healthcare model? As an example: the SF-12 evaluates symptoms and processes related to every-day living. Patients can give objective answers to questions such as: To what extent did pain symptoms hamper your day-to-day work? (Replies ranged from "not at all" to "extremely").

TABLE 8: SF-12 EXCERPT 1

8.	To what extent did pain symptoms hamper your day-to-day work in your profession or at home during the last four weeks? Pain	Pain: 4P
	☐ 1 Not at all ☐ 2 A little bit ☐ 3 Moderately ☐ 4 Quite a bit ☐ 5 Extremely	

Also, the SF-12 includes questions that take medicinal answers into account, e.g.: How would you describe your general state of health? (Replies ranged from "excellent" to "poor").

TABLE 9: SF-12 EXCERPT 2

Item	Subscale	Summary scale
1.	How would you describe your general state of health? Physical functioning	Physical functioning: 4P Normal functional ability, symptom free
	☐ 1 Excellent ☐ 2 Very good ☐ 3 Good ☐ 4 Fair ☐ 5 Poor	nee

This is in comparison to the interview, which can provide subjective answers that include opinions and personal statements.

As an example: When the interview question below was posed, the patient answered adequately (answers were sufficient and met the target of the question).

TABLE 10: EXAMPLE INTERVIEW QUESTION

W: "How well do you feel today and your general condition?"F: "I feel good. I am fine, thanks. Since a few weeks I feel o.k."

There is an overlap between two specific measurements that focus firstly on particular aspects of health and disease and secondly on population-specific measurements. Health- and disease-specific measurements focus on specific aspects of cancer or QOL and patient satisfaction.

Both generic and disease-specific QOL is affected by different factors, which are not only health or disease related-parameters. As Padilla, Ferrell, Grant, and Rhiner (1990) pointed out, examples of such factors are composite attributes that are relevant at a particular point in time, e.g. mood, being strong, social-relationship, familial situation, psychosocial stress, income, socioeconomic status, religion. QOL, in general, shows negative and positive attributes of well-being (Bowling et al., 2012) (see Table 15 to Table 17).

If patients make personal statements about their quality of life, these statements are subjective. As Bullinger et al. (1995) stated, satisfaction is highly emotional and is, therefore, often subjective. Sirgy (2012) elaborates upon this approach by considering the aspect of life satisfaction: emotional well-being is viewed as happiness and cognitive well-being as life satisfaction. According to Sirgy (2012), quality of life is the sum of happiness, life satisfaction and the absence of ill-being. Therefore, subjective QOL is what the patients perceive as the difference between expected and received needs and expectations through participation in primary life domains (Asadi-Lari et al., 2004). In this research project, the researcher identified three categories as being significant for evaluating quality of life: interpersonal, medical and organisational categories. According to Padilla et al. (1990), attributes of general organisational functioning under cancer-specific therapy belong to the category of physical well-being with structural requirements. Attributes on facts of the medical cancer disease, emotional and perceptive attributes (attitude from an affective - emotional and cognitive - perceptive point of view) as well as accomplishing attributes belong to the category of quality of life. The last category is interpersonal well-being, which covers the attributes of social and role functioning.

It is important in health care to explain what PS indicates and the current role of health-related behaviour (Linder-Pelz & Struening, 1985). Linder-Pelz and Struening (1985) considered that patient satisfaction can serve as an outcome in-

dicator to evaluate quality in health care as a predictor of behaviour for compliance and frequently changing conditions. To distinguish between satisfaction as a more cognitive evaluation, Linder-Pelz and Struening (1985) characterise patient satisfaction as a positive attitude. Mood and emotion are also cognitive evaluations. Attitudes are general evaluations, objects and issues and defined as affective. Linder-Pelz and Struening (1985) interpret perception as recognition of information. The associations between perception as cognitive and attitude as affective can be explained as attitudes are what we think about the perceived object.

<u>Perceptions and attitudes</u> may involve both a cognitive evaluation and an emotional reaction: perception versus expectations (Pascoe, 1983). Satisfaction involves comparing perceptions of how the service was performed with the expectations that one had beforehand. The evaluation of the discrepancy between expectation and perception of reality is subjective and is also emotionally influenced (Keinki et al., 2016). As Tate and Forchheimer (2002) argue, well-being is a more emotional (affective) component or attribute of QOL; the three life domains of QOL, PS and well-being are self-perceived. Life satisfaction is assisted by emotional and social support and seems to be closely linked to inner experiences and less connected with physical limitations (Rønning et al., 2016).

#### 3.4.3 Summary

Previous studies in this research area have been quantitative. According to (Tranfield, Denyer, & Smart, 2003), quantitative studies are ranked as the highest quality level in evidence-based medicine. The researcher adopted the quality criteria of qualitative research based on Daly et al. (2007) and their hierarchy of evidence for qualitative methods.

The knowledge gap addressed in this research is to what extent the quality of oncological care can be estimated by way of a qualitative approach in a single outpatient unit. The qualitative research approach is more suitable for this research because of the small number of patients. According to Stake (1995), quantitative research is limited to a small number of variables in a large sample size. Qualitative research seeks for the unexpected and expected relationship and interdependencies. A distinction between quantitative and qualitative research is that in qualitative research, each research question seeks to use data that can be directly interpreted rather than using scales and measurements as in quantitative studies. Stake (1995) mentioned the need to preserve 'multiple realities' of the case. Interviews are the main road to viewing these multiple realities.

The introduction section 1.2 points out that a quantitative questionnaire cannot be statistically significant to answer complex questions in a small unit. Therefore,

only a qualitative approach is feasible. In ambulatory medical clinics, quantitative multicentre approaches cannot be used to evaluate the quality of oncological treatment promptly. In addition to this, small numbers of patients in single medical clinics mean that quantitative approaches are statistically not feasible. Multicentre quantitative surveys are neither prompt nor focused on a single practice.

Several aspects were considered during the process of selecting the chosen interview and questionnaire. Taking into account that the perspectives and personal situation of each patient are important, the goal of this research was to juxtapose questionnaires and interviews to develop assessment tools that can adequately evaluate an individual patient's needs (Morgan, 1998). Firstly, the target group was relevant. Because the participants were older and severely ill, the researcher deemed it better to ask questions personally in a face-to-face interview. Secondly, and for the same reason, it was important to choose a questionnaire of an appropriate time and length. Thirdly, resources needed for a questionnaire are significantly lower than those required for an interview (no travel costs, less time-consuming and less personnel). Fourthly, the quality criteria were considered.

The researcher aimed to use a holistic approach. By collecting information from the patient's point of view regarding beliefs and behaviour, personal views, perceptions and expectations, the researcher hoped to evaluate the quality of oncological care. An optimised method and procedure needed to be developed. The interviews were performed first, followed by a short-form questionnaire two weeks later. Validated instruments like questionnaires are commonly used in oncological practices, but relevant questions like individual patient perspectives are often missing. That is why the interviews were performed first, gathering data which were then compared with the questionnaires. Questionnaires were used to monitor how patients perceive QOL and PS. In this study, the analogous SF-12based questionnaires collected data about QOL. Flick (2014) stated that interviews are often applied in case studies and that the focus is on a specific issue depending on a specific case. Sale et al. (2002) supported this statement, arguing that interviews can also serve in conjunction with other methods to corroborate findings. This combination approach compares different methods and tools to answer different kinds of questions and can throw light on previously unseen aspects. The combination of these tools is philosophically and practically sound and convincing.

# 3.4.3.1 Development of the questionnaire

Past studies focusing on QOL are contradictory in their findings because of the multidimensionality of the construct and the individuality of the patient's physical, psychological, social and functional subjective health (Cox, 2003). QOL, both in

general and in the case of specific chronic diseases, can be measured in many ways. Which aspects of the QOL and PS are most important remain unclear, but it is known that QOL and PS do affect patients with cancer diseases (Calman, 1987; Velikova et al., 2004). This thesis seeks to elucidate which attributes of PS and QOL play a significant role in the experience of cancer patients.

Good QOL consists of physical and psychosocial well-being aspects. Therefore, it is necessary to evaluate QOL and PS in a qualitative survey. Sale et al. (2002) add that in health research, quantitative methods alone cannot evaluate the lived experiences and social interactions of the patients. The use of patient-related outcome (PRO) measurements to understand patient experiences of cancer has become a key topic in research on health care quality in the past decade (LeBlanc & Abernethy, 2017). PRO is reported by a patient about his or her health status and is not an interpretation formed by a doctor or staff (Speight & Barendse, 2010). Stone, Murphy, Matar, and Almerie (2008) agree that patients cannot address all of their concerns or present all of their thoughts in questionnaires. Because of the illnesses and personal requirements of oncological patients, it is not possible to come to any significant conclusions about the patient-related outcome (PRO) using uniquely quantitative methods (Huebner et al., 2014). As Huebner et al. (2014) point out, the PRO questionnaire has the advantage of including different assessments and generates data that can be useful both for clinical practice and individual treatment. A negative aspect of the PRO questionnaire is the frequency with which patients must fill out the questionnaire and the amount that patients must write to fill it out. The PRO questionnaire is also limited in that it is uniquely symptom-based.

For practical purposes, the analogous standardised questionnaire short-form (SF-12) was chosen in this research as an "add on" to obtain information about QOL. The interview that the questionnaire was combined with was more suitable for performing an in-depth exploration of PS (see TABLE 53: Comparison of different questionnaire types generic and disease-specific).

#### 3.4.4 Quality criteria

These quality criteria are described here because they provide the reader with clarification and help explain the researcher's choice of qualitative methodological paradigm. The quality criteria are as follows:

- 1. The provision of an ideally precise and holistic description of the observed situation as well as a systematic comparison of data from different perspectives (triangulation).
- 2. Interpretation of data against the background of the daily practice and

3. In alignment with the literature and scientific interpretation.

## Reliability and validity of the assessment

The researcher is aware that in qualitative interviews, bias on the part of the interviewer and interviewee can impact the validity, objectivity and reliability of the research. To mitigate bias, the researcher chose a qualitative semi-structured interview. The researcher limited herself to the discussion of the 15 interview questions regarding organisational, interpersonal, medical and social aspects of the treatment process presented in the semi-structured interview and did not pose any additional questions.

The following steps were taken to mitigate bias: A quiet, suitable place was chosen for the interview. Questions were as neutral as possible and were worded clearly. Respondents could answer questions using their own words. Questions were written in a fashion that encouraged unbiased and truthful answers. The interviewer showed respondents that she was listening attentively, that she was interested in the provided answers and that she wished to hear more about the experiences being described. This motivated the respondents to provide expansive and detailed answers. The researcher neither made judgemental comments nor expressed emotion in response to patient answers. It was a balancing act to maintain objectivity and at the same time, exercise professional empathy when receiving the personal information being shared by the patients.

The relationship between interviewers and interviewees is typically defined before an interview starts. It depends on several factors, including the time and location of the interview, the individual personalities of interviewer and interviewee and the expectations with which the interviewee enters the interview. The interviewee has the chance to talk in detail about their points of view. If in the interviews conducted for this research an interviewee did not understand a question, the researcher would reword the question in a way that strived to maintain openness and neutrality. The researcher listened actively to all participants and did not make comments of any kind regarding the relevance, sufficiency or validity of participant answers.

The only role of the interviewer was to pose the questions outlined in the semistructured interview. If the interviewee strayed from the topic at hand while answering a question, the interviewer asked the question once again. There is only a slight chance that the interviewer influenced the answers of the interviewees because the interviewer refrained from commenting on patient answers, and from discussing anything at all other than the pre-developed interview questions. The interviewer possessed an open attitude, the capacity to restrain herself from imposing personal interpretations on the statements of study participants and the ability to listen. hus, the risk that the emotions or prejudices of the interviewer biased the results of the interview is limited.

The technique of member-checking could not be considered in this study because the study participants were critically ill, and it could not be assumed that the participants would be alive or in a state to answer questions by the time that the study data had been obtained and interpreted. None of the participants interviewed in this study are still alive.

This research project would have had to consult an external oncologist to ensure intercoder-reliability. The researcher decided against doing so because one of the primary research questions in the study asks to what extent QOC can be reliably evaluated by one single outpatient unit. Had outside sources been consulted; this question would not have been adequately addressed. The importance of transference and countertransference of the interviewee, essentially, on the content and structure of the responses were limited because of the above-mentioned steps taken by the researcher. This is in line with the results of a study performed by Khoshnazar et al. (2016), which identified a connection between the factors of communication in an interview (ability to listen, no comments and interpretation, open attitude and following the structured guideline) with the ability of medical staff and patients to build a trusting relationship. One desired outcome of the tool developed in this research was that medical staff – and not just external researchers – can perform this semi-structured interview and come to conclusions about the QOC provided by individual outpatient units.

Regarding the strategy mentioned earlier to mitigate mutual influence, the researcher performed the process of clear assignment of questions and nodes. The interviewee was required to answer all 15 predefined questions of the semi-structured interview. The content of the answers was allocated to 31 thematic nodes to address the problem of transference and countertransference. Ultimately, the possibility of transference, countertransference and bias could not be excluded entirely through the processes of a semi-structured interview, thematic allocation of questions and nodes and subsequently, the evaluation of nodes.

Being aware that mutual influence as a problem exists, the interviewer tried to mitigate this through reflexivity. Finlay (2002) explained that reflexivity is the process by which researchers scrutinise their motivations regarding assumptions

about, and interests in, the subject matter. It is through reflexivity that the researcher practices ongoing self-critique and self-appraisal (Koch & Harrington, 1998).

The personal, interpretative nature of interview questions may run the risk of being biased and influencing the participants, but they can also be a platform for developing new understanding, as Denzin and Lincoln (2009) point out. The aim of this research is to produce knowledge in the context of patients' perceptions, needs and subjective points of view. This subjectivity of the researcher and the participants is part of the research process and builds a picture of the patients and the researcher's impressions and feelings.

The knowledge and skills the researcher brought into the research process are based on specialised training for haematology and tumour diseases and working for more than 20 years in an outpatient oncological medical clinic. Understanding the conditions which brought about the research problem, it is now relevant to report on the background of the study and the researcher's interest in the topic.

During her everyday work, she gained professional experience and knowledge about concerns, needs and social interaction with tumour patients. She was inspired through the experience and started a master study with the topic: Implementation and integration of oncological palliative care and home care support in a specialised practice. The theoretical discussion in this field and reflection of her everyday work with severely ill tumour patients under a critically reduced perspective of life, helped develop the research questions beyond medical questions of objective response rates: To evaluate the quality of oncological care, based on the quality of life and patient satisfaction in the single outpatient unit.

The questionnaires of the PASQOC reference study which identify PS and QOL quantitatively were for the researcher an orientation. As a prospective reflection of her experience with the tumour patients, she performs in her qualitative study an in-depth interview to gain more detailed and comprehensive information about patient satisfaction. The QOL questionnaire should be evaluated qualitatively.

The researcher is aware that working with critically ill patients and the dying process of the patients may influence her perception and interpretation of the research process. However, maintaining a professional distance is an essential requirement for her everyday work.

To conduct the interviews, the researcher required a range of skills and expertise. Given the researcher was both integrated into the research process and part of the caring team, represented a potential conflict of interest. One potential bias in most qualitative studies is that the interviewer might bias the answers given in the interviews. Interviewee responses might show beliefs generated during the interview rather than pre-existing beliefs. Furthermore, it is almost inevitable that an interviewer transfers his or her existing attitudes and beliefs to the interviewee to some degree. To avoid this bias as much as possible, the researcher employed different strategies based on the detailed interviewer guide (Figure 8: Overview of the interview guide). In future studies, employing multiple interviewers could considerably increase the objectivity of the interview data.

The question of whether the results would differ if other interviewers had been employed cannot be answered with certainty. However, it is noteworthy that the study results displayed remarkable similarities to those of the PASQOC study. In addition to this, the results of the interviews were widely supported by the more objective questionnaire data and were therefore deemed by the researcher to be a sufficiently objective interpretation of reality.

The researcher's reflections and neutrality on the statements form part of the interpretation, and the researcher wrote memos filled with observations, meanings and outcome at the end of the interview protocol. After reading the transcript of the interview protocol, the starting point for reflexivity began with the researcher thinking aloud about the spontaneous comments and thoughts of the interviewees who were recorded and documented. The researcher observes problem-relevant events involved in the entire interaction of the research process. See, for example, one part of patient 6's (SG) interview. Patient 6 (SG) answered somewhat reluctantly but was ultimately empathetic and positive despite her incurable illness. Both interviewees 6 and 10 (SG and EW) were asked the question "a: How do you feel today?" and "b: What outcomes do you hope will result from your treatment at this medical practice?"

TABLE 11: INTERVIEW ANSWER (SG)

SG:

"For me it is more important to think that I had never been ill, used to think nothing could happen to me, my husband did all the work and had all the responsibility. Now, I can see it is impossible for me to keep my previous life and I make my choices every day, I'm very grateful for all the help. Yes, the doctor talked to me, very open, fair and square. While before, I felt fine, I have hope, I'm still convinced that there must be a little bit more...".

A second example of the researcher's reflexivity can be found in the interview of patient 10 (EW I). The patient is unwilling (see also the five stages of Kübler-Ross and Kessler (2005)) to adequately answer the interview question. Kübler-Ross and Kessler (2005) proposed that there are five stages of grief: denial, anger, bargaining, depression and acceptance. In this case, the patient produced a series of statements demonstrating his emotional states of denial and anger without accepting his disease. He recognised in a frustrated way that there was no hope for him and therefore no possible answers to these questions.

TABLE 12: INTERVIEW ANSWER (EW)

EW:

"For me, the doctor thought and decided together with me what therapy to give me. You know, I know all of this. I am aware that these are questions to which I'm not in a position to answer. I'm not asking questions I do not want to hear things that I do not want to hear".

In these examples, the researcher acknowledged that she could always influence the participant and vice versa and was, therefore, also a part of the research process. The role of the researcher in a case study is to evaluate the merits and short-comings of the study (Stake, 1995). However, the researcher recognised that a wide range of different perspectives and viewpoints leads to bias that must be acknowledged when discussing the credibility of the findings and the appropriate use of quality criteria during the research process. To ensure quality and reduce bias, the researcher developed the strategy of a set of appraisal questions (the later evaluation of nodes) and for each question a set of attributes which she called code-words (the so-called next nodes). This guideline idea was influenced by Denzin (1978); Flick (2014); Hammersley and Atkinson (2007) and also by Pobe and Ziebland's (2000) suggestions for qualitative research in health care. The researcher created a system of grouping themes and code-words, which built the

so-called family clusters. This is relevant for the analysis and findings chapter because the search for meaning is often the search for patterns, correlations and interdependencies (Stake, 1995).

In this research, 15 interview questions and 31 code words were identified. They included all the key features and themes the researcher found relevant for answering the research questions. For each question, the researcher developed a few context-related attributes (code words). More specifically, e.g. for question "k": To what extent do you require additional psychological support? A selection of context-related code-words could be: "concerns, acceptance of the disease, fighting against cancer, enough time, quality of service and adequate treatment": with the expression of the related code-words as a need for more or less support. "Fighting against cancer": patients express that they are willing to fight/ or not against cancer during their treatment and to use all options made available to them. It could be a clear indication of the beginning of depression, adaptation or deprivation. "Enough time": Patients express having enough/not enough time for doctor-patient-conversation. "Quality of service": meaning the scope of service where the patient evaluates the organisation on quality and vice versa.

In this study, it was necessary to determine the relative weighting of nodes and questions to assess the quality of oncological care. These different weightings were important because they provided a fuller picture of the patient's experiences and perceptions. For the researcher, it was not relevant to count how often a patient mentioned, e.g. the word "hope". Patients often state the word 'hope' multiple times, both in cases of a good or poor prognosis. Patients have hope if they undergo the treatment process. They imagine that life could be better someday. Every human being expresses hopes. In this research, the context of the expression was relevant. The researcher developed the weighting of data (node +3/-3) to evaluate how relevant the expressed words were to the evaluation of the quality of the medical practice. For example, patient NJ, like many other patients, expressed the word hope positively more than ten times in response to questions "b", "c", "d", "h", "l", "j", "k", "l", "n". However, finally, the results showed that hope is neither relevant for the evaluation of QOL and PS, nor QOC.

Based on the researcher's subjective interpretation of the 15 interview questions, which resulted in the relative weighting (+3 and -3) and classification of 31 codewords, the researcher built many individual combinations. This considerable number of combinations meant that bias could mostly be balanced out. However, only a tendency in this research can be captured and not a generalisability. Stake (1995) comments that the genuine business of a case study is particularisation and not generalisation.

Another approach to reduce bias is the structure of the conceptual comprehensive research framework (see more in chapter 4 methods). The previous chapters described constructivism as a theoretical and philosophical approach and explained how the research framework and concepts were derived from a qualitative approach. Baxter and Jack (2008) pointed out that the constructivist position is problematic when considering neutrality and objectivity. The chosen approach - as several authors have described – uses the method of interviewing to develop a dialogue between the researcher and the participants. The researcher did not use member-checking as an opportunity to engage the participants with their interview reports again. This would have been impossible because of the severity of the illnesses and the short lifespans of the patients as they died shortly after the research project phase (Mays & Pope, 2000) (see also p. 115).

This research, as previously mentioned, was conscious of respecting quality criteria. The use of quality criteria for constructivist qualitative research could lead to a new understanding that may have beneficial effects for patients. It is nearly impossible to list all potential validity threats and their influence on the conclusions, but the researcher is aware that bias is a part of the research process and explained how she would deal with the possible influences in positive or negative cases. However, the researcher also considers her personal beliefs and world view.

Yin (2009) discussed quality criteria in detail in his case study designs. Hammersley and Atkinson (2007), Kvale and Brinkmann (2009), and Langenhoff, Krabbe, Wobbes, and Ruers (2001) all assert that validity receives more attention than other quality criteria like trustworthiness, credibility, dependability and conformability. As with any other empirical research methods, case study quality criteria must fulfil the requirements of validity and reliability. These quality criteria give indications of the quality of the case study. As Yin (2009) argued, quality criteria must be considered in advance depending on the chosen design and should not only be used retrospectively to proof the design.

In this qualitative case study approach, specific evaluation criteria are essential. The first important criterion is validity: does the collected data meet the requirements of the scientific method and the chosen indicators? The second criterion is reliability: is the action taken reliable? In this case, the underlying construct of the quantitative PASQOC questionnaire was used to improve the interview questions.

## Validity and reliability

Quality criteria can also be used to ensure reliability. The documentation of data and the recording quality are key when assessing reliability criteria (Flick, 2014).

Silverman (2006) suggests note-taking (writing notes to reinterpret the data and to clarify the procedure after the interviews), which increases the reliability of the research and offers an opportunity for researchers to check on the dependability of the research. To ensure reliability in this research project, memos were written at the end of the interview phase so that the researcher's impressions and the statements of the interviewee were not altered in any way over time. It was at this point in the research process that the interpretation of the collected data began.

## Counteracting effects and techniques for confirming rigour

The researcher used triangulation as a method to ensure validity and reliability in her research. Jick (1979) argued that triangulation entails combining complementary methods, e.g. scaling, to quantify the qualitative measurements. This combination of different paradigms can increase credibility. In this case study research to support the results from the qualitative data and the interview questions, the researcher intended to compare these answers with the coding words and the assigned participants. Stake (1995) argued that by cross-checking the generated data from participants with other information sources with a "within-method of triangulation", a researcher can minimise bias. In the data analysis and data synthesis sections of this thesis, the researcher followed a systematic, well-described process. In doing this, she aimed to ensure that another researcher could come to similar conclusions if he or she used the same approach and methods.

The researcher followed Morse (1991) suggestion to supplement her primary qualitative data generation methods with a supplementary method (quantitative data adapted into a qualitative approach). This allowed her to see if divergent findings resulted from different data methods such as semi-structured interviews and questionnaires. This means that qualitative data from interviews and the information from questionnaires were combined in the same study. Morse (1991) used supplementary method quantitative data adapted into a qualitative approach to come to divergent findings. The researcher of this study used this idea to compare her interviews and questionnaires and to determine whether the patients answered consistently in both the interview and questionnaire. If one finding gets closer to the qualitative interview one, then the triangulation should be given more weight towards the validation of the research findings.

# 3.5 Research design

As a researcher, it is possible to use a concurrent design to compare findings using both qualitative and quantitative data sources at the same time. It is important to take into consideration that qualitative data from semi-structured interviews and

questionnaires can be transformed into a quantitative score set that can provide validation for each data set and create a sound basis for intervention and vice versa (Maxwell, 2012); for example, as Cox (2003) pointed out, using semi-structured interviews to gather qualitative data and questionnaires. Researchers can evaluate factors such as patient experience and QOL in a holistic manner; this does not mean to replace or disregard one or the other of these tools.

The researcher began her research process with the semi-structured interviews. Unlike Cox (2003), the researcher did not wish to encourage the interviewees to respond to, be influenced by, or reference the questionnaires during their interviews. Also, Cox (2003) study is longitudinal from the quantitative questionnaire to qualitative interview using a mixed-methods approach. Cox (2003) studied 83 patients with two different methodological approaches, combining a quantitative design with a qualitative design to assess QOL. Patients first filled out quantitative questionnaires and then participated in qualitative interviews. Interestingly, only the in-depth interviews revealed individual perspectives from the patients' points of view. The data obtained from the questionnaires had no meaningful statistical relevance.

Much like that of Cox (2003), the studies of Nguyen Thi et al. (2002), Nguyen et al. (2011), and Jenkinson and al. (2002) argue that age, family status and types of care influence PS. These researchers show in their studies that many factors influence PS and QOL. Jenkinson and al. (2002) sought to identify indicators for specific aspects of care. Comparatively, as in the PASQOC study, they identified what aspects influence PS and what factors influenced a patient's willingness to recommend the medical facility. The authors explored in a questionnaire survey to what extent patient satisfaction is an important indicator for the healthcare sector. Also, Jenkinson and al. (2002) commented that several factors, such as expectations and perceptions of optimal care, influence a patient's overall satisfaction.

This project focuses on an analysis of individuals and patient experience. The scope of the case study is limited by the following factors: time, place, activity, definition and context. Each of these factors is based on findings from former literature and the researcher's experience. As Yin (2013) suggests, these propositions from pre-existing literature can be compared and contrasted with new data. The use of data sources, such as interviews and questionnaires enhance the credibility of this case study. As mentioned, the researcher combined qualitative semi-structured interviews with a questionnaire analogous to the SF-12 questionnaire to reach a holistic understanding of the participants being studied. With the help of the computer database NVIVO, the data materials were organised and stored for later use.

Yin (2013) suggests six methods of reporting a case study: linear, comparative, chronological, theory building, suspense, and un-sequenced. Comparative case studies incorporate both qualitative and quantitative data to gain an understanding of the case context and examine causality. Causality refers to the results, impacts and particular outcomes of the intervention.

## 3.5.1 Case study approach

The researcher chose to employ a case study approach to gain a real picture of the patients' needs and expectations. It was first necessary to determine the unit of analysis – the primary unit that is being analysed in this study – or as Miles and Huberman (1994) put it, the "what I want to analyse questions". In this case study, the researcher creates a two-part unit of analysis: the individual patient and the groups with and without ASC (the organisation in which the groups interact).

In this research, the chosen case study deals with a group of patients in the specific context of a cancer outpatient unit. A goal was to understand how and why their illnesses influenced the participants. A case study, which in this case is an individual unit, can be used to determine whether the propositions made by a researcher are correct, or whether some alternatives may be more relevant. A single case study can also outline a contribution to knowledge and, as Yin (2013) argued, can challenge, confirm or extend theory building to refocus future investigations in a specific field.

According to Yin (2013), the goal of a case study is to gain an in-depth understanding of a single or small number of cases. Silverman (2004) argued that case studies are for trying to test a theoretical framework by using it in real-world situations. In qualitative inquiries, however, the case study is more interested in the behaviour of the individuals (Yin, 2013). A case study is also compatible with many different data sources (Hammersley & Atkinson, 2007). These statements are from different key authors in case study research but contain meaningful information for this research.

To describe social processes and the existence of multiple realities while doing a case study, this research focuses on social interactions between participants in the health care system (such as doctors, nurses, staff) and patients. It examines patient approval and diverging interpretations of QOC in cancer patients. The case study design was appropriate for this research because it allowed the researcher to observe the behaviour of patients in the real-life context of the outpatient unit. As Yin (2013) points out, an experience cannot be studied outside of the context in which it occurs. In this research, the keyword factors identified in the literature review were tested to determine whether they were currently being implemented

in practice, useful and/or sustainable. The purpose of the proposed single case study was to determine the features of the new health care model and to compare these with the former one.

## 3.5.2 Triangulation

A goal of this research is to understand how qualitative methods can be used to gain an understanding of a given situation, attitude or behaviour. Triangulation is used as part of the validation process to compare results. A case study generally involves in-depth research into one case or a small set of cases and is a bounded system (Yin, 2013). Yin explains triangulation aims to gain a rich and detailed understanding and to generate general data from interviews, surveys, questionnaires and observations in up to four cases. Creswell (2013) suggests that combining these methods is advantageous for researchers because they can gather multi-faceted data. For instance, triangulation is a practical way of comparing the results from two or more different methods of data collection or different data sources and as Baxter and Jack (2008) state, to obtain credibility. Mays and Pope (2000) explain that empirical data is consistent and trustworthy. The threefold approach of quality criteria of consistency, trustworthy and reflexivity refers to the sensitivity with which the researcher has assigned and handled the collected data.

The triangulation used in this study compared interview and questionnaire results, nodes, and both patient groups with and without ASC. As Mays and Pope (2000) point out, triangulation could be one way to improve validity in qualitative health care studies. The comparisons of two different data methods compensated the weakness or strengths of the other. Mays and Pope (2000) see triangulation as a comprehensive and encouraging reflective analysis of data and not solely a test of quality criteria. Triangulating the qualitative data from nodes and interviews within two patient groups did not lead to a mixed-method approach because the researcher did not triangulate quantitative and qualitative methods. The questionnaire was transferred from a quantitative to a qualitative evaluation process. This research examines two groups of participants in one single outpatient unit. These subunits are "embedded" (between- or across-method) and are referred to as "the Units of Analysis". If a patient's quality of life is assessed in an outpatient unit, the patients are the unit of analysis (see p. 118).

All approaches have in common the fact that they start with a research problem, followed by the research questions, the data generation, analysis and the evaluation of the findings/results. In a case study research, a single case is typically selected to illuminate a particular issue. An event is studied using multiple sources such as interviews, observations and documents to develop a detailed analysis of

the case. Case study research is an in-depth examination of a single case and provides a systematic way of looking at events and understanding why things happened the way they did. The goal of a case study is not to make changes or take action (Jick, 1979). All research designs have a common issue, which is that they aim to produce universal theories (Easterby-Smith et al., 2012). Local knowledge is essential in management and organisational research to have theoretical value and focus on local practices. Combining methods is a way for a researcher to view a situation from many different perspectives (Hammersley & Atkinson, 2007). Conversely, combining data from different sources can lead to inaccurate research based on insufficient and superficially analysed data. Hammersley and Atkinson (2007) and colleagues note that qualitative research can contribute much more value than a positivistic approach allows. In this particular case study, verification and falsification fit more with the post-positivistic paradigm of "constructivism" because this research must advocate critical subjectivity and the researcher's experience "based on perceptions" (see p. 91).

Miles and Huberman (1994) describe in detail the process of combining several methods such as interviews and observation, recording and collecting data from multiple sources. While having a cumulative view of data appears to be a good idea, this research does not use a mixed-method approach. This is because a mixed-methods approach would neither improve the reliability of the research nor cause the researcher to feel reassured and make progress on the research project (Sale et al., 2002).

#### 3.5.2.1 Methods of data generation through triangulation

The research began when patients had been undergoing chemotherapy for two months. Patient reports of QOL and PS changed in response to their chemotherapy treatments, pain and the burden of their diseases. The method of triangulation was used to assess better the ability of the instruments to look at the unexpected or expected changes to corroborate evidence. There are several types of triangulation. Denzin (1978) pointed out that data triangulation can be used to ensure data robustness when two different data sources are used in the same study. Methodological triangulation in social science is the use of more than two methods combined in the same study and requires the connection of two paradigms (Jick, 1979). Morse (1991); Morse and Richards (2002) propose performing triangulation "within a method". By this, they mean that it is helpful to use the qualitative method primarily and the quantitative method as an auxiliary method (see TABLE 13: Methodological triangulation).

TABLE 13: METHODOLOGICAL TRIANGULATION

Methodological triangulation (within-method)	More than one data collection procedure from the same design approach	Using a survey and secondary data for quantitative analysis
Methodological triangulation (between- or across-method)	Employing both qualitative and quantitative data collection methods	Using interviews and a survey

Tashakkori and Teddlie (2010) stated that the use of triangulation depends on the philosophical position of the researcher. Miles and Huberman (1994) pointed out that qualitative researchers document a topic with different sources of data to triangulate information and to provide confirmation of the research process. The table above is based on Thurmond's (2001) conceptual framework and presents the different forms of triangulation. The researcher used triangulation to gain a comprehensive understanding of patients' needs using multiple data sources, including interviews and questionnaires. The comparison was made between answers from patients to the interview questions and the values and relevance of these answers for defining the quality of oncological care, and also a comparison of both groups of patients with or without ASC. The researcher was interested in detecting divergent or convergent answers for strengthened results and identifying possible vulnerabilities.

## The rationale of why particular methods were chosen

As mentioned in the literature review, standardised questionnaires cannot measure patients' own experiences of care and satisfaction. They are not sensitive enough for this purpose (Fitzpatrick et al., 2006). Therefore, the researcher chose a generic questionnaire to look at factors other than specific illness and treatment issues. Calman (1987), one of the first researchers to evaluate QOL, suggested that there is a difference between health-related QOL and QOL in general. It is not the case that all patients suffering from illnesses have poor QOL. QOL encompasses an individual's views and experiences at any given point in time. Only individuals themselves are qualified to describe their QOL. Researchers should, therefore, understand that it is important to differentiate between QOL dimensions which are influenced by diseases and their treatments and those that are not associated with illness (Calman, 1987).

Cella and Stone (2015) and Jenkinson and al. (2002) suggested that a combination of questionnaires and interviews could be a new way of studying QOL. An aim of

this research was to assess the relationship between QOL and PS with data generated by interviews and questionnaires. Information from the interviews and questionnaires helped identify the symptom categories that were causing patients the most problems. They also provided insight into the individual QOL and PS of particular patients. The researcher did not focus on disease or treatment-specific side effects. Therefore, she did not use a health-related questionnaire.

While HRQOL questionnaires offer more information about the toxicity of treatment or the worsening of the condition, this kind of information is more useful in a clinical setting. The researcher's main goal was not to generate clinical data, but rather a deeper understanding of a particular group of severely ill patients. In this study, it was required that the patients participate first in the qualitative interviews. The questionnaire survey followed two weeks later because previous research has shown fundamental differences in the thought processes and behaviour of patients during their treatment (O'Boyle et al., 1993). The short sequence of two weeks was chosen by the researcher to minimise these influences. This survey was not intended to provide a quantification or generalisation of interview findings, but rather to demonstrate, when possible, similarities and differences between the two different methodological approaches answered by the patients. This research does not adopt the perspectives of Hammersley and Atkinson (2007), who combined approaches to "produce a complete picture". This research triangulates the facts by examining where the data intersects "in depth rather than breadth".

As Brinkmann et al. (2007) have argued, there is no "gold standard" concerning small studies with few participants. The number of participants has nothing to do with the scientific quality of the analysis. Generally, questionnaire surveys question a large number of patients to measure factors such as HRQL (Waldron, O'Boyle, Kearney, Moriarty, & Carney, 1999). Both teams of researchers see fundamental problems in using questionnaires with predetermined answers to measure QOL. While questionnaires alone could provide relevant information regarding treatment and health, this research adopts the perspective that such tools cannot adequately measure patient points of view or patient opinions about treatment.

# 3.6 Research methodology summary

The methodology chapter has outlined the reasons that support the choice of research context and design, starting with the research topic and arriving at the data collection procedures. The objective of the planned research was to explain, to uncover and to identify the structures, mechanisms and improvement options that can be obtained with the research approach of a single case study within the

research philosophy of social constructivism. The single case study in a qualitative methods approach is appropriate to investigate complexities within the context of the real-life situations of the participants of the study.

## 3.6.1 Application to this research

The qualitative approach of this research emphasises process and meanings and is based on the constructivist worldview that reality is socially constructed (Guba, 1990). Qualitative and quantitative paradigms result in different philosophical and methodological discussions. Comparing qualitative and quantitative paradigms allows a researcher to gain a complete understanding of the topics being studied (Denzin & Lincoln, 2009). The initial idea of this research was to identify those topics with the most significant influence on PS and QOL and to be able to evaluate QOC.

A single case study is appropriate for this qualitative inquiry because the constructivist, epistemological post-positivistic position of this research is interested in the meanings and feelings of patients in real-life situations. A case study alone is not able to provide the richest and most holistic information for the researcher and is seldom representative. However, qualitative research is not governed by any strict rules, and as Silverman (2004) pointed out, many productive qualitative studies depend on single cases.

It is pertinent to focus on the new model of ASC. On the one hand, it remains to be seen whether a qualitative approach can be used to evaluate the QOC for oncological patients in Germany's two healthcare models. On the other hand, the chosen research design and strategy fit with the development of semi-structured interviews and analogous standardised questionnaires which can produce findings that will help illustrate complex health care issues of patients undergoing oncological treatment. The researcher decided to begin with the interview phase and follow with the questionnaire to avoid having patients be influenced in the interview by the questions they filled out in the questionnaire.

It is necessary to have a health care system that meets the needs of patients with severe diseases. The doctoral thesis attempts to close this research gap with a qualitative approach for the oncological patients in an outpatient unit undergoing the new model of ASC. This research adopts a constructivist approach that listens to the thoughts, behaviour and feelings of patients who are involved in the inquiry. In the following chapter 4, the researcher justifies how she generated data through methods such as semi-structured interviews and analogous SF-12 questionnaires in a case study approach. The purpose of the inquiry is to understand patients' situations. This means that it is necessary to find an appropriate approach that can

carry out the aims set out by the research. This research examines the relationship between PS and QOL and the QOC for patients undergoing oncological treatment in a single outpatient unit. It also expands the limited body of knowledge relating to the perceptions of quality of care among patients who are being treated under the new ASC healthcare model.

This chapter has philosophically discussed the objective and subjective aspects of QOL and PS. It has also distinguished between general, generic and health-related QOL. The researcher argued that high ethical significance must be considered due to patient alignment, shared-decision-making, response-shift and self-determination of chronically ill patients in relation to this research. The following presents the ethical considerations of the researcher and discusses how QOL is regarded as being morally binding in the medical context (Woopen, 2014).

# 3.7 Research ethics and data protection

From an ethical point of view, this research is a necessary contribution and could produce positive and identifiable benefits for the patients involved in this study. From the medical perspective, QOL and PS are important criteria that can be used to decide whether or not appropriate therapy should be continued or stopped or whether the actual quality of life is severely limited (Radoschewski, 2000). When dealing with chronically ill, palliative patients, therapy aims to obtain the highest possible quality of PS and QOL.

Important ethical factors in this research are the researcher's use of information, recommendation and documentation and the informed consent of the participant. It is the researcher's responsibility to inform the patients about the possible impacts of participating in the interview. The researcher must also take the patient's situation into account when asking questions (Woopen, 2014).

As Woopen (2014) points out, QOL has high ethical significance. The goals of her study are related to moral binding of quality of life. She argues it is not just a question of the nature of the quality of life but also the life span. Philosophically she equates high ethical significance with "ethical behaviour", a successful life, and the personal sense of life of every single person (Woopen, 2014). The importance of ethical relevance, so that the patient can be self-determined and make decisions along with the doctor about further treatment, requires useful information for patients. However, Woopen (2014) argues that these data from research and method for subjective QOL data collection need to be further developed. The separate allocation decisions regarding cost- and utility in health care are not considered at this point.

The purpose of an Ethics Board is to ensure that severely ill patients are protected from harm, but it takes into consideration the benefits of research for the greater good of the vulnerable groups when permitting research to be carried out with patients (Ethikrat, 2011). In Germany, ethical approval from an Ethics Committee is only needed for clinical trials that use medication or perform biomedical research on human beings. The interviews and questionnaires employed in this thesis *did not* include any biomedical information or treatment of the participating patients. However, the situation in the UK is different, because any research with vulnerable individuals requires approval from an Ethics Committee. Following the ethical principles of the Declaration of Helsinki, the researcher needs to ensure that the benefits outweigh the risks for participants being part of the study (World Health Organization, 1955).

## Information about the German legal environment:

Research projects in Germany only need to pass ethical approval in clinical trials of medical products and drug application. Standardised questionnaires and interviews need no ethical approval if the research is concerned with the management of quality. This is the case for this research study, where the focus is on the effectiveness of quality management in the outpatient care unit of an organisation. The only 'risk' factors in this study are not to the research participants' life or wellbeing, but the potential unreliability of the data due to the participants' volatile state or that their answers may be 'socially desirable' responses.

High-quality standards were applied in the research about ethical consideration such as granting and maintaining confidentiality and anonymity of all research participants as well as the right for them to withdraw at any time. The researcher developed the informed consent form and clarified the questions in general. After time for consideration, participants could give their agreement to the informed consent to the researcher. The researcher used both interviews and questionnaires to obtain valid and detailed information. As a consequence of the interviews, patients had to address their terminal illness and talk about their cancer which could be distressing. However, their deteriorating health is a situation they are dealing with on a daily basis and research suggests that patients often find it comforting to talk to an empathic listener (Khoshnazar et al., 2016). Patients were aware that, if the situation required it, they could pause their interviews and quickly arrange an appointment with the attending physician. The information gained through the interview process was only shared with the physician at the patient's request. If the patient's situation worsened, the researcher was prepared to stop the interview at any time and make an appointment with the doctor. Both the researcher and participant were permitted to pose questions at any time during the interview.

As the research was undertaken as part of doctoral study at a UL higher education institution — ethical approval was required. Therefore, the University of Gloucestershire research ethics principles and procedures were followed, the researcher ensures this was sought and gained (see the following documentation and risk management (Ethikrat, 2011; URDC, 2016 - and information in Appendix B).

# Research process under ethical consideration

The research strategy in this thesis focused explicitly on the needs of patients with chronic and long-term illnesses. These patients require continuous, comprehensive care that is based on their personal needs and expectations. Each participant in this study was allowed to talk freely in a pleasant and quiet environment. If the patients had requested it, the information obtained from the interviews could have been passed on to the doctors involved in future treatment. (see Attachment I, Attachment III: Interview for patients after informed consent and see Ethics Approval table 54, 55, 56).

The study was entirely voluntary, and the participants were only included in the study if they provided written consent. The participants were instructed not to write their name or initials on the questionnaire to remain anonymous. Participants could refuse to answer any of the questions and could withdraw from the study at any time without penalty or loss of privileges. All participants were subjected to the same conditions and were treated equally. The researcher recorded the answers from the questionnaire and interview on a Microsoft Office spreadsheet with the use of her identification system. The researcher did not discuss results from any individual part of the research with anyone.

The literature that the researcher reviewed indicates that most studies that have been conducted to date in this field use quantitative research methodologies when evaluating healthcare. The employment of these methods was intended to gain a better understanding of patients' needs, perceptions and impressions of life in general while they undergo medical treatment. The results of this study provide a conceptual framework that could be utilised to enhance professional approaches in the care of oncological patients. The researcher had to consider whether her findings would have ethically relevant positive or negative consequences for the participants. She also strived to identify and assess possible risks and complications before the research began. The researcher guarantees that no participant comes to harm or must face relevant consequences. In this research, all patients were granted anonymity, and the researcher ensured that they did not come to

harm or under pressure. There was neither risk for the researcher nor the participants. Actions were taken to protect all personal data. All participants had the option of rejecting the use of gathered data and digital devices such as tape-recorders or cameras. It was established that all records would be destroyed at the end of the process, five years at the latest after the conclusion of the research. The research was based on the freely given informed consent and the researcher employed no covert methods to collect data. The participants were fully informed about the aims, duration and possible consequences of the research. The researcher guaranteed that the participants would not be pressured into participation and had the right to refuse participation at any time and any stage of the research project.

Risks and implications of social desirability and voluntary participation in the survey may have influenced patients so that the data and drawn conclusions will probably be higher than in other cases. Social desirability was more of an issue in face-to-face interviews than in standardised questionnaires because of the intensive dialogue and the fact that the researcher and patient knew one another from the treatment process (Hammersley & Atkinson, 2007). One way to prevent participants from answering untruthfully to questions is to be extremely careful in the wording and selection of the interview questions. In this study, patients were assured that there were no right or wrong answers, no acceptable or unacceptable responses. In addition to this, anonymity was maintained, and participants were given the assurance of high quality and correct research. In this case, member-checking as re-tests after a period were not feasible. However, the constant comparison method and the triangulation ensured reliability and confidentiality. Posed questions were short enough that the respondents could answer them quickly without imagining what ulterior interests the researcher may have had.

Hammersley and Atkinson (2007) argue that the researcher is always a part of the study and what the patient says is always influenced by the interviewer and of course, by the situation. As mentioned previously, bias is a risk factor the researcher cannot eliminate. It is important to understand how and in which way the researcher can influence what the participant says and how this influences the validity of the conclusions the researcher draws from interviews. The researcher role is highly debated in qualitative research. This research concerns the researcher-researched relationship.

The researcher in this study was an insider because she was part of the medical team as well as the interviewer. This research is grounded in the traditions of human social science research, and in-depth interviews produced data material. During the interview stage, the researcher considered it important to listen to and to

show respect to the patients. In doing so, she contributed to the trusted caregiverpatient-relationship, which is essential in the qualitative research process.

The researcher set up a continuous risk management plan to minimise project risks and provide answers to critical questions. Factors such as the treatment environment and the severity of patient illnesses may have enhanced the fear and insecurity experienced by some participants. The researcher developed the informed consent form and clarified the questions in general. After personal time for consideration, participants could give their approval of the informed consent form to the researcher (see Appendix B Methodology, table 54, 55, 56). The researcher used both interviews and questionnaires to obtain valid and detailed information.

As mentioned in the chapter about quality criteria, the researcher developed strategies for a quality assessment to reduce bias. The first strategy by the researcher was to consider the analyses which could be biased; the next step to receive transferability (the so-called external validity), and finally to compare the collected data with a systematic comparative procedure. By comparing codes over and over again, the researcher achieved a fuller picture of the patient's perceptions and experiences. To fulfil the criteria for quality and good clinical practice, the researcher followed the principles of ethical codes and respected the need to reduce the risk for participants of having any disadvantages from participating in the study. An aim of this research was to contribute new knowledge in a scientific and ethical way for the benefit of patients even though there were possible sources of conflict. It was important that the researcher be aware of ethical risks such as transference and countertransference that were associated with the research process. Despite this, the researcher always respected the rights of the participants that were linked with the voluntary given informed consent, sufficient and adequate information and guaranteed confidentiality that all information would be kept private.

This study focused on collecting data from a vulnerable group of patients. The data pertained to the patients' subjective perceptions of a severe illness, their subjective experience undergoing chemotherapy treatment and their quality of life and satisfaction during this phase of life. In some cases, the interview questions forced patients to confront the reality of their life-threatening diseases and the severity of their illnesses.

When participating in the interviews, patients could not help but be confronted with their illnesses. That said, a range of situations in a patient's everyday life lead to scenarios in which they must face aspects of their cancer disease. During the individual interviews, the researcher could stop the interview and intervene under

controlled conditions. Patients were also aware that in case of conflict, they could quickly make an appointment for a personal meeting with the attending physician.

The researcher considered that this internal crisis for the participants may not be ethically correct in the sense of avoiding unnecessary harm, but she also understood that patients would be confronted with their incurable disease in their everyday lives and such information is nothing unexpected or unfamiliar. The researcher tried to counteract and deal with the issues of bias. It is inevitable and unavoidable, but reducible. She also attempted to provide the data at a time that did not burden or stress the patients and respect the privacy of patients (no focus or group discussion). The semi-structured interview allowed the researcher to limit the length and intensity of the discussion. Another counteracting approach is the interpretation of data. The researcher made sure not to embarrass the participants by way of patients feeling classified, categorised or compared with others. An important part of this qualitative research was the researcher's subjective interpretation of results. The researcher did not judge patients on an individual level. The data from interview statements had nothing to do with the participant's personality. The results of the study could not influence a patient's treatment or diagnostic situation. Patient confidentiality is ever-present in the outpatient unit that was studied and was respected by all members of staff, doctors and the researcher. In a small sample size, it could be easier to identify the study participants when using parts of the interview or statements in the thesis. To avoid this problem, the researcher developed her numbering and identification system (see section 4.3 data processing). The researcher will store the data for five years, avoiding traceability of patients, colleagues, family members or other participants by encryption of names, age, gender and addresses to protect the patient.

Depending on the research questions, quantitative and qualitative methods are consistent. However, both methods have overlaps and grey-zones. One can consider quantitative elements in qualitative research and vice versa. Therefore, critical reflection is necessary to ensure the validity and reliability of the research. The enhancement of validity and reliability in qualitative research does not depend on the number of participants or the statistical principles for quantification (Denzin and Lincoln (2009). Denzin and Lincoln (2009) emphasise the lived experiences of those who are under study and the value they bring at that single moment of their interview situation, which must be considered valid and sustainable.

From the researcher's point of view, both paradigm traditions have resources for thinking out of the box. It is possible to improve quality by using numbers in a qualitative approach and pay attention to meaning, classification and interpretation in a quantitative study. The procedure in this research was to get information

from the participants during the interview. The researcher sought to determine what was important to them, what their needs and perceptions were, and how they viewed their treatment process and their own PS and QOL. This interview data offered specific information (PS) about the posed interview questions.

For rigour in qualitative research, the researcher built versions of methods and data documenting the process of analysis in detail following the approach of Pope and Ziebland (2000), who suggest that a skilled researcher could analyse the data the same way and come to the same conclusions.

A continuous risk management plan was set up to minimise project risks and provide answers to critical questions. The researcher knew factors such as the treatment environment and the severity of patient illnesses could enhance the fear and insecurity experienced by some participants.

### Risk management

The following steps were taken to prevent conflict situations:

The researcher developed the informed consent form and clarified the questions in general. After personal time for consideration, participants could give their approval to the informed consent to the researcher. As a consequence of the interviews, patients had to come face to face with their illnesses. A broad range of situations in a patient's everyday life forces them to confront the effects of their cancer diseases. The interview setting had the advantage that patients confronted their illnesses in a controlled setting. Patients were aware that, if the situation required it, they could pause their interviews and quickly arrange an appointment with the attending physician. The treating doctor only obtained data from the interview in the case of the patient's request. If the patient worsened, the researcher was prepared to stop the interview at any time and make an appointment with the doctor. Both the researcher and participant were permitted to pose questions at any time during the interview.

Statements or indications made by patients, which revealed in-depth, personal conflicts were not discussed in the study, as there is no direct relationship between these personal conflicts and the aims of the study. The researcher, when appropriate, was prepared to stop the interview. The researcher guaranteed the confidentiality of all participants and did not pressure patients into providing information.

The researcher respected the current regulations regarding data protection (URDC, 2016). All data was stored privately in a locked office, and only the researcher has access to the data. As mentioned above, the researcher made use of medical help if necessary. In this case, the patient was excluded from the study.

Also, at the patient's request, the information obtained from the interview could be passed on to the doctors that will be involved in future treatment.

### About the patient data confidentiality:

Patient data will only be shared with the treating doctor in case of an explicit wish of the patient. The medical treating doctor is legally obliged under the Hippocratic oath to maintain patient confidentiality. The researcher will keep the data for five years after the study has been finished. All data will be destroyed after five years. The participants were reminded that the researcher would present her results at conferences and publish the results in an academic journal. No participant will be identifiable by name. All codes of patients feature consecutive numbering.

The researcher was aware from the beginning that ethics was an important part of her research. She understood that it is not easy to find solutions to problems for every case that may arise. Also, the ethical implications show that QOL and PS, through a comprehensive understanding, are very important for continuous improvement in health care research and beneficial for patient care and treatment.

# 4. Methods

From different research questions, the researcher received different types of information. In the methodology chapter, the researcher discussed the general principles that guided her through the research process. In the research method chapter, the researcher determines the specialised tools and techniques that she used to achieve the goals of the research, which are the constant comparison method and triangulation of interview, questions and nodes. As mentioned in the methodology chapter, the researcher developed a strategy that provides the successful use of the best method. The researcher explains how she acquires data generation and data analysis with a variety of qualitative research methods (Morgan, 1980).

### 4.1 Introduction

As discussed in the previous chapter, much qualitative research is based on data generation methods such as interviews rather than on numbers and statistics (Pope & Ziebland, 2000; Velikova et al., 2004). In qualitative research, special emphasis is placed on "how and why" questions. The research questions are "howquestions". A case study is used to explore the as yet un-researched question of whether patient satisfaction and quality of life of cancer patients can be used to explain the quality of oncological care in a single outpatient unit. This research aims to evaluate the decisions and experiences of a specific group of chronically ill patients. The conceptual framework seeks, both in the generation of data and the analysis of interviews and questionnaires, to identify areas of patient care that are promising, relevant, or yet to be developed. The findings from this research should develop new insights into the experiences of patients with chronic illnesses. The procedures developed initially in the literature review and methodological plan are compared and contrasted by way of the triangulation technique. The qualitative research methods are, therefore, separated into individual phases that are explained in the following chapters.

Section 4.1 opens with an explanation and justification of qualitative data methods. Focus is placed on the qualitative evaluation of a patient's everyday life through the collection and analysis of written and verbally expressed opinions. In section 4.2., data generation methods are discussed. In section 4.3, data processing methods are established. Section 4.3.1 focuses on transcription and in 4.3.2 and 4.3.3, coding rules and thematic coding are described. Section 4.3.4 details the role that the software program NVIVO plays in the data generation process. Section 4.3.5 explains the comparative case. Section 4.4 is data analysis with a comparison of the used methods as a part of analysing the data for a better un-

derstanding of the findings from the research. Section 4.4.1 contains detailed information about the guided interviews, section 4.4.7 the questionnaire, and section 4.4.8 the triangulation process.

# 4.2 Data generation

The previous sections discussed the development of the interview and questionnaire. It is now time to discuss the survey methods and study procedure used in this research. As Curry, Nembhard, and Bradley (2009) point out, quantitative research alone cannot completely address the research questions so a qualitative approach can be helpful to provide insights into causal mechanisms. The researcher explains different methods to generate data from a qualitative approach. This chapter explores which sampling methods and frames were used, why they were appropriate, and why they were chosen. The participants in this study were patients with severe gastrointestinal tumours undergoing chemotherapy. The survey method was split into two phases: the first ten patients were not treated under the ASC model while undergoing their chemotherapy. The next ten patients received their chemotherapy under the ASC model. The sampling was purposeful. That means that unlike quantitative studies that can examine large and varied groups of participants, this project studied only a small number of participants, all of whom were selected by the researcher as being appropriate candidates for the study.

The decision to include patients in the study was based on the following inclusion criteria: candidates were new patients who had been undergoing oncological treatment at least two months. All participants suffered from severe gastrointestinal diseases. Life expectancy was more than six months. Participants had to be at least 18 years old, had to speak the German language and had to have the authority to sign the informed consent. All participants who did not fit the inclusion criteria were excluded from the study.

The results of this research concentrate only on qualitative analysis. Validity considerations were taken into account to deal with all potential external issues (see section 3.4.4). A detailed interview and questionnaire in its final version are presented in this section: (see TABLE 58: Interview guide German - English in chapter 11 Appendix C: Methods) and explained below.

## 4.3 Data processing

It was particularly important in this research to consider quality criteria when

choosing the research methods. Yin (2013) refined and extended the quality criteria to include consistency and validity. For example, it was necessary to document all procedures diligently and clearly to minimise errors and reduce bias, which could impact the study's internal validity. As mentioned in the methodology chapter, this inquiry followed the quality criteria of a qualitative research approach. It is known that the consistency of the research and the results obtained can confirm the credibility of a study (Yin, 2013). The researcher is aware that following this line of reasoning, the data must be accurately recorded and correctly documented so that the research results can be reproducible and reliable. Therefore, the researcher chose methods, by way of triangulation, that resulted in stable, reliable data. The following paragraphs devote time to the definition of important terms and the description of the coding process, which greatly influenced both the research and the data analysis.

### 4.3.1 Transcription process

Transcription in social science is a set of rules for the transformation of verbal or nonverbal communication into written text. Audio or video data serve as the basis of transcription (Bortz & Döring, 2007; Kuckartz, 2007). In this thesis, all interviews were transcripts from a tape recording to written, verbal data in standard German (see FIGURE 13: Transcription process). The nonverbal communication such as gestures, facial expressions or pauses and dialects were neglected because they were not pertinent to the on-going research process. Each dialogue section was transcribed by the researcher and numbered line by line. The switch from interviewer to interviewee was marked from beginning to end in each interview. Transcription rules developed by Kuckartz (2007) such as word-for-word transcriptions, exact quoting and anonymity (it should be impossible to trace citations back to an identifiable person) were carefully attended too. It was noted that any changes to or reductions of the text influence the data analysis and the research findings.

The goal of transcription is not to focus on individual words, but rather to gain a contextual overview of the presented data. The text unit obtained by transcription became the reference and unit of analysis (individual patients and the group with and without ASC) that was then used in the coding process with the help of NVIVO.

# 4.3.2 Coding rules

This section outlines the coding rules used in this research. Coding, as Kuckartz (2007) states, is, on the one hand, an important point of orientation for the analysis of qualitative data and, on the other hand, a general tool for understanding and interpreting texts. Coding involves assigning categories and concepts, or so-

called codes, to information to segment and structure it with the research objectives. Category means nothing else than the term 'labelling'. The researcher assigned labels to the so-called nodes, which were either one word, several words or short sentences (Kuckartz, 2007). Coding does not separate words from their original contexts; however, coding allows for the idea that individual words can be interpreted in different fashions.

The coding process strives to provide an improved overall understanding of recurring motifs in any given text or speech. The categories mentioned below and the codes are strictly linked to the responses from the interviews to start the process of abstraction of the data (Gale, Heath, Cameron, Rashid, & Redwood, 2013). All patients, after a two-month chemotherapy phase, participated in a face-to-face interview that lasted 20-25 minutes. In the interview phase, patients were only asked about their subjective perceptions from interpersonal, medical and organisational categories. The semi-structured interview was divided into three thematic categories:

- <u>Interpersonal</u> (9 items, e.g.: appreciation doctor-staff, assistance and support by the physician, concerns, consolation, hope, integration and personal needs, trust in the doctor, worries and well-being);
- <u>II.</u> <u>medical</u> (10 items, e.g.: acceptance, accessibility, adequate treatment, alternative treatment, cooperation, enough time, fighting against cancer, information about a diagnosis, therapy and side effects of therapy);
- <u>III.</u> <u>organisational</u> (10 items, e.g.: continuity of support, coordination, personal stress, quality of service, appointments, waiting-times and travel distance, transparency and information, recommend the unit).

Two weeks later, all patients were given a standardised questionnaire analogous to the (SF-12) with 12 items to fill out.

Table 60, Table 61 and Table 62 in Appendix Methods C depict the three main codes used in this research. The approach of developing code words in this thesis was inspired by the reference studies of Kleeberg et al. (2005) and Padilla et al. (1992). The researcher defined coding categories that best represented the content of the researcher's interviews. A detailed description of the coding process and the selection of codewords is included in section 4.3.3 thematic coding.

The first step in the coding process was to organise all code words into a coding frame, which was arranged in alphabetical order. The second step was to define the main codes and sub-codes during a first reading of the interview text. For this, an inductive-oriented perspective was adopted: all text passages were categorised

in "code boxes" chosen by the researcher. Table 14 (example of first category building) exemplifies five code-building categories. At the end of this process, saturation, or a point when no more new codes or sub-codes were created, was reached. Coding, and later composing, divided the text passages into smaller units. Hopf and Schmidt (1993) argued that unlike researchers using quantitative statistical methods, qualitative interviewers could manually identify, interpret and analyse complex relationships if they have a transcript of the interview data. Hopf (2016) defined a four-step code-evaluation procedure:

- Firstly, codes should be developed, and main- and sub codes should be defined.
- Secondly, the text should be coded with the help of a structured coding guideline. The relevance of the codes can be ascertained by counting how often they appear in the text.
- Thirdly, how dominant they are in comparison to the other codes.
- Fourthly, an overview of the case-coded words should be created. Organising the codes into a table is important because it allows the researcher to see specific data patterns that might not otherwise be evident.

TABLE 14: EXAMPLE OF INITIAL CATEGORY BUILDING

Five Steps	Examples	Constructed Code	Code #
Definition as clearly as possible of themes for the categories	e.g. category of subjective meaning and expectation of treatment at this medical practice	Assistance and support by the physician	2
		Adequate treatment Alternative	12
		treatment Information about	13
		treatment Coordination	18
		Transparency and information	22 27
Approach determined in detail	Line by line analysis of interview text. If the content fits to the below mentioned question the text will be assigned to the category		
Building new categories	Relevant text passages build a category e.g.	What are your main concerns relating to your treatment?	3
Assumption of existing categories	Decision making of each interview text existing category or building a new one.	Interpersonal: Appreciation- assistance and support Trust in the doctor	1 2 7
Building main- and sub- categories	Set of categories will be structured in straight line order and three main categories remain	Close to practice: ad1. Interpersonal ad2. medical ad3. organisational	Ad1: 1-9 ad 2: 10-19 ad3: 20-29

The idea for thematic codes (see 4.3.3 Thematic coding in interviews) used in this thesis derived from the PASQOC reference study (Kleeberg et al. (2005). In line with Miles and Huberman (1994) and Saldaña (2015), the researcher used thematic coding as an interpretive approach to pull data material together from the three thematic coding categories (interpersonal, medical, organisational). Definitions for the chosen codes were provided to avoid misinterpretation during the data analysis phase. A structured guideline helped the researcher organise data in such a way that the chance of identifying a high number of coincidences was increased (Hopf, 2016). Hopf (2016) argued that given the complexity of a topic, it is neither practical nor efficient to replace one sufficient method with another.

Finally, an in-depth analysis of selected cases should be performed (see FIGURE 14: Process description of a qualitative content analysis (own source) in Appendix C: Methods). In the following chapter, the idea of building categories will be explained in detail.

## 4.3.3 Thematic coding in interviews

Classical content analysis is based on the idea of building categories and analysing empirical data by sorting them into categories. This research categorised information by way of thematic coding (Mayring, 2014). Thematic coding is the compilation and interpretation of all text segments assigned to the same coding words. Comparative thematic coding seeks to find connections between different codes (Kuckartz, 2007; Mayring, 2014).

The "in-depth analysis" focuses on single case studies. As Kuckartz (2007) stated, in-depth detailed case interpretation can help the researcher find connections and determine whether the research objectives are applicable or not. The thematic coding process is divided into four phases:

- Firstly, finding themes with the same coding words
- Secondly, refine coding
- Thirdly, comparison and connections between different codes
- Fourthly, case analysis and interpretation of all text segments

The first phase, composed of six steps, can be viewed in FIGURE 15: Development of a code flow chart (own source).

One aim of this research was to find similarities between single persons, characteristics and single categories by comparing and contrasting thematic codes. Fine coding was used to build the main ones and sub-codes to accomplish this. As the flow chart of the coding process indicates, interpretation of the categories is the last step of a multi-stage process. Quantitative aspects (weighting of nodes) are relevant to this coding process. However, the final results of the data analysis and synthesis in this research were interpreted not with numbers and percentages but with words so as to incorporate the personal views of the interviewees. See FIGURE 15: Development of a code flow chart (own source) in Appendix C: Methods.

Thus, in this research, the case-related and case-oriented graphical presentation of regularities using Excel sheets lead from interpretation to knowledge. In the interpretation of results, it was possible to show which person said which code words. As this qualitative research deals with words and their meanings, it was of interest to note how many words were uttered, how often and in which context. An example of this was the word "hope". It was not relevant for the researcher to count the amount of time the word "hope" was uttered in the interviews because every patient expressed hope - often more than ten times — when discussing longer life, personal circumstances, treatment and condition in the interviews.

However, the word hope is important for themselves because "hope always dies last!"; for interpretation, in each situation, the researcher weighted the codeword to evaluate how "good or bad" this word could be for the quality of oncological care. The results of the study showed that hope is neither relevant for the evaluation of QOC, nor for QOL or PS.

The Excel sheets consist of columns (sub-codes) and rows (participants) (see all Excel sheets in 11 Appendix C: Methods). This case study aimed to compare and contrast the impressions of individual patients in two groups of cancer patients. The following questions lend themselves quite obviously to such a study: Which persons are similar, in which way? Which characteristics and features are relevant for answering the research questions and which are not? Different Excel sheets were created to present the data in such a way as to reveal patterns to answer these questions. Following an empirical approach (see methodology chapter), the tables and Excel sheets were tested by "if-then" questions. The goal was to assess the research questions as a concept map of the relationship between categories and concepts.

#### 4.3.4 Software NVIVO

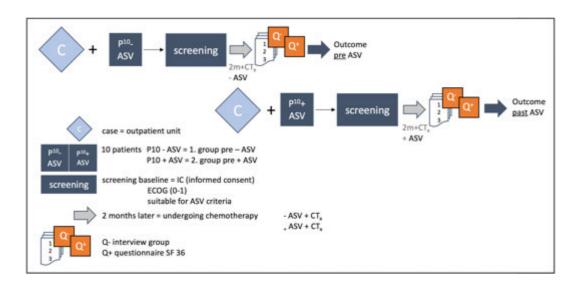
Specialised qualitative data analysis (QDA) is often used to provide support and systematisation in research practices. A useful form of QDA is computer-assisted qualitative data analysis software (CAQDAS). In contrast to quantitative data analysis tools, CAQDAS systems cannot provide a meaningful interpretation of the researcher's work (Kuckartz, 2007). QDA software only helps to make the data manageable, facilitate coding, write memos, perform search functions and refer to cross-references. QDA software can also help researchers visualise data analysis and can perform word-based frequency evaluations. Bortz and Döring (2007) claim that QDA software supports the structuring of interpretative work and is suitable for use in different approaches to qualitative analysis. Following this line of thought, QDA can assist with interpretative content analysis and cross-case analysis (Kuckartz, 2007; Mayring, 2014).

#### 4.3.5 Comparative Case

This project took the form of a comparative case study. A single case study examines one single feature or functionality of one individual case based on specific research questions. In doing so, different methods of data collection and data analysis can be combined. In this single case study, two groups of participants were compared who were undergoing different treatment options (with or without ASC). This case study linked theory with practice to produce understanding (Bortz & Döring, 2007).

A comparative case (CC) depends on the how and why questions of an intervention or outcome, the timeframe, and how the program is being implemented (Goodrick, 2014). An understanding of the context as well as understanding the success or failure of the outcome of the research is important in a CC. As Goodrick (2014) explains, a CC can also be useful in explaining why and how an intervention works (or does not work) when combined with another intervention, e.g. sequentially or consequently followed from one to another group. An in-depth description of the single case study is found in the conceptual framework (see FIGURE 9: Conceptual framework (own source)).

FIGURE 9: CONCEPTUAL FRAMEWORK (OWN SOURCE)



The specific case of an outpatient unit relates to the research questions. One group of ten participants undergoing cancer treatment under Germany's former healthcare model was questioned. Two months later, the second group, undergoing cancer treatment under the new ASC model, was questioned. The comparative case study was based on Yin's case study research methods (Yin, 2013). As aforementioned, the focus in this CC study was placed on two different data collection methods: interviews and questionnaires. The case study process was conducted sequentially, based on the exploratory research design and the initial propositions (Bullinger, 2000). As a matter of principle, Bullinger (2000) points out three different measurement approaches: sequentially an existing instrument can be transported in another context or language (e.g. SF-36); in a parallel approach, instruments from a different culture can be compiled (e.g. EORTC) along with cooperative development of a questionnaire, e.g. from a WHO working group.

# 4.4 Data analysis methods

This section presents how the researcher proceeded with the research strategy, in particular the interview and questionnaire. This section focuses only on procedures for the analysis, not on interpretation. A qualitative researcher, as Greenhalgh and Peacock (2005) state, must use precise methods of data analysis that are structured and reproducible. Chapter 5 Findings will provide an interpretation of the data.

#### 4.4.1 Interviews

For a research project to be successful in obtaining meaningful data, the researcher must choose appropriate methods. In this thesis, two forms of data generation were employed: interview and questionnaire data. In this research, the interview questions were semi-structured to offer the opportunity for the interviewe to express his/her own problems and the interviewer to specifically funnelshape the questions. The standardised questionnaire analogous to (SF-12) was used as an "add on" to the interviews to assess QOL, PS, and QM data.

#### 4.4.1.1 Semi-structured Interviews

The sample in the case study consisted of a total of twenty patients, all of whom suffered from advanced gastrointestinal cancer and were being treated at the same outpatient unit. A semi-structured interview was drafted. The participants had the option to answer freely and neutrally, agreeing, disagreeing or refusing to reply. There were several questions without pre-formulated answer options. The interview began once the participants gave informed consent. The interviewer explained in detail the reason for the interview and asked for the willing participation of the patient in a questionnaire two weeks later. The procedure of the interview schedule was as follows:

In the introduction phase of the enquiry, the background of the research was explained to participants. The interviewer explained why the interviewee was selected and how long the interview would last. The informed consent form was explained to the participants as well as what would happen with the data afterwards. The written and signed agreement protected the data of participants and held the researcher to uphold ethical standards. The interview itself began with a warming-up phase that consisted of small talk at the arranged and appointed time in the practice.

The main task of the interviewer during the interview phase was to manage the course and time of the discussion. It was necessary for the interviewer to differentiate between uncommunicative participants and chatterboxes and to focus the conversations on relevant information to keep the momentum going. All conversations were recorded per audiotape. At the end of the interview, the participants were thanked for their participation. The interviewer ensured that the participants seemed at ease and felt well before leaving. Finally, the interviewer wrote down interview memos after each meeting, commenting on the dialogue, the atmosphere and the situation of the interviewee.

# Assessment section

In this case study research, the work was carried out sequentially. The first step was the qualitative semi-structured interview. This order was chosen for several reasons. Firstly, the aim of the interview was for the patients to speak freely. They need not be influenced by any questions asked in the questionnaire. Secondly, when talking freely, the patients could provide information to the researcher without filling in answers to questions, which would have been difficult given the severe nature of their illnesses. Thirdly, the patients were only asked to describe their subjective perceptions and needs. They talked about questions and described their feelings. This is an opportunity they do not have in the questionnaire.

The analogous SF-12 questionnaire was the second step. The questionnaire, which was not individualised, was to address the more objective elements of patients' healthcare experience that may not have been described in the subjective interviews (Stiel et al., 2011). Stiel et al. (2011) point to the need for short and simple QOL assessment tools in oncological treatment to reduce the patient's burden and effort under their cancer treatment. Ideally, this would result in a few questions to minimise the use of unnecessary items. However, when evaluating QOL and PS, it might be difficult to find only a few adequate items that can cover all dimensions of the complex multifaceted phenomenon.

## Assessment construction

After the warm-up phase and introduction, the participants were asked three preliminary questions regarding their general well-being, their hopes and their sorrows given their current situation. These questions ensured in ethical ways that the participant was in a sufficiently healthy mental condition to participate in the survey. A list of words was used to build the questions from the thematic block I-III (Questions a-o) (see TABLE 36: Interview guide German - English).

These words derived from the PASQOC study and other previous QOL and PS studies (Kleeberg et al., 2005; Padilla et al., 1990). The words selected were designed

to evoke answers about patient feelings. Patients answered in their own words. The researcher was looking for words which expressed emotional expressions like happiness and luck, sadness and loneliness, nervousness, irritation and anxiety; statements to gain information about attitude, values and interests of the interviewee.

The following three sections (I-III) of the interview include four questions each (a-o). The interview begins with the so-called internal aspects I (outcome indicators), and then continues to patient education II (process indicators) and finally information and accessibility of care and treatment environment III (structural indicators). These three sections are cornerstones of the research process and based on Donabedian's (1980,1988b) structure-process-outcome principles and stem from the area of interpersonal, medical and organisational characteristics. For this reason, the orientation focused on the validated PASQOC questionnaire from Kleeberg et al.'s (2005) research. The questions were specifically chosen in the semi-structured interview guide. The four elements of the interview guide are depicted in FIGURE 8.

The interview began with questions about communication and empathic behaviour because patients are accustomed to these kinds of questions (Question a-c). Questions (h-k) concerned the domains of process quality aspects and patient education. Touched upon were medical aspects of diagnosis, treatment and side effects as well as shared-decision making, patient-doctor-relationships and trust. The accessibility of care and treatment environment was explored in questions (l-o). These questions asked more about structural indicators like cooperation with others, coordination of waiting-time and the willingness of the patient to recommend the institution.

#### Pre-test

A pre-test was performed with two participants. The interviewer revised all questions several times and pilot-tested on two patients for clarity and comprehension. The findings were used to improve the actual interview questions and, if necessary, add a few new questions. After the final interview questions were decided upon, they remained unmodified. If an answer could not be sorted into one of the related groups, they were put in the category "far away from practice", which meant that the social, financial or personal issues discussed did not have to do with their medical experience. No participants had difficulty understanding the terms or questions presented during the interview. In all cases, the semi-structured interview was administered first, and then if the patient was willing and able

to proceed, the questionnaire was completed. All questions posed in the interviews and questionnaires were answered, and the study finished with 20 interviews and 20 questionnaires.

The interviewer in the interview setting carefully explained all queries that could have been misconstrued. The researcher was aware that some of the questions posed in her interview pertained to sensitive topics. However, these questions were important for answering the research questions. Therefore, the researcher considered how the interviewee might feel about answering the questions and was attentive when the participant was confused or addressed concerns about a topic. The researcher thoughtfully considered and evaluated each question, most of which stemmed from other evaluated research projects such as Kleeberg's reference study (Kleeberg et al., 2005). A trial run of the interview was performed to eliminate misunderstandings. Before the face-to-face interview, a predetermined, written script was used to explain the study to the participant. The participant gave informed consent according to the guidelines of the University of Gloucestershire. When the consent was given, the tape recorder was turned on and the interview was started. All interviews were audio-tape-recorded and afterwards transcribed. For transcriptions, no software was used.

All patients had incurable gastrointestinal cancer and were patients of an outpatient unit in Germany. In an additional Excel sheet, the gathered information about age, gender, family status, distance from practice (km), and profession was collected. Patients under 18 years old or patients who were disorientated, confused, had poor pain control or were unable to speak German were not included in the study (see Table 70, 71 and p. 311 demographic data).

## Introduction and analytical classification

It is important to describe the data categorisation process that took place in this research. The audiotaped recorded interviews from 20 participants resulted in a total of 149 comments by patients who were not being cared for under the ASC model and 150 comments by patients who did undergo ASC. The majority of comments made during the interviews ranged from 0 to 7. The comments were grouped into the following three main categories: I. interpersonal, II: medical and III: organisational. The category was not coded or classified if the answer could not be assigned, was mismatched or did not relate to the research questions. During the initial phase of the coding process, a category system was developed based on the interview answers. This system was refined inductively during the second and third rounds of coding. The process ended once no new code words could be created (Bortz & Döring, 2007). This active and creative categorising process was very

similar to the method of grounded theory, but it was not a multi-level staging procedure, and there was no open coding classification for building key competencies (Corbin & Strauss, 2008). As a guideline for the coding procedure, categories were built based on the research questions. This helped to see what could be achieved with the phase of systematisation and compression of the gathered data.

# A detailed description of the analysis process in phases (all tables: chapter 11 Appendix C: Methods)

The results of the coding process performed in this research are presented below. Silverman (2006) also addressed reliability in several ways to enhance a good quality-tape-recording and transcription of the collected data. One of the key issues to do with interview responses is the coding process. The coding process selected allows passage and themes to agree and work consistently with code names.

### Phase 1-4:

In the first step, the interview was read thoroughly, and a memo was written which highlighted relevant text passages and noted first impressions. In a second step, the interview answers were categorised into the three main related codes. In a third step, the complete interview text was coded and assigned to the subnodes. Individual words were not coded, but rather entire concepts, or sentences. It was important to take context into consideration during the coding process. Additional questions were also coded if necessary. An important criterion was the fact that many sections of text were coded multiple times. Sometimes participants answered questions in a way that was either divergent or indifferent. Often the answers were categorised in several different sub-nodes.

## Phase 5-8:

The material was structured into a theme-related matrix which comes from the NVIVO software package. Several tables and Excel sheets were built, which sought to find points at which the sub-nodes intersected (see Table 63 to Table 65). Sub-nodes were classified according to the following scale (also reported in Table 76: node evaluation with and without ASC -3+3) for positive and negative attributes of QOL. This needs further explanation. The valuation of +3/-3 means a patient rated a node clearly negative or positive. This could mean a negative or positive assessment with regard to a patient's own values or with regard to the quality of the practice. A poor rating for patient and practice was assigned with grade -3. A good rating for patient and practice was assigned with grade + 3. Indifferent grade 2 means a tendency to a satisfactory result. Grade 0 was assigned when no identification was applicable. Grade +1/-1 was not carried out in favour of a better differentiation of the results.

Answers were categorised to several sub-nodes if they were theme-related.

### TABLE 15: EXAMPLE INTERVIEW QUESTION B)

b) What outcome(s) do you hope will result from the completion of your treatment at this medical practice?

10PR: Hope means that all things will become good. I would like to travel a lot because that was what I liked for most of my life. Last year I was broken and felt depressed but now I accept the things as they are and feel better. I would like to travel in summer. I live my normal everyday life.

Coding category: sub node: hope, acceptance, continuity of support and worries.

On the other hand, patients could provide multiple answers to a question. In this case, the patient expresses hope as a positive (+3) node and less continuity of support alongside worry (-3). This leads to a different (positive or negative) evaluation and grades and thus higher sub-node sums (also talkative patients in contrast to taciturn patients).

### TABLE 16: EXAMPLE INTERVIEW QUESTION J)

j) Do you feel that you have been sufficiently informed about the possible side effects of your therapy? Information on side effects.

9AT: No, ... I work all day in my garden, mowing and chopping. Sometimes my grand-children can help,... but my wife is in hospital and I am alone at home, ...I do all the homework... cooking, cleaning, shopping ....I have two daughters but they have no time .. my wife requires an oxygen mask....I don't want to ask someone for help.

Coding category: far from practice social and personal conflicts. (He said nothing about the question and chattered about mowing his lawn and his family situation)

### Phase 9-12:

Case overview and interpretation of a case. The purpose of discussion content analysis sees an overview of several interviews in a table. This should be used to compare a smaller group of participants (<15-20) (Kuckartz, 2007). The case overview in NVIVO reported all 20 cases, displaying features and patterns that are relevant for the research topic and research questions.

#### 4.4.2 Node evaluation

The first step was the <u>node evaluation</u> in a category system (see Table 72: Node Evaluation With and Without ASC -3+3). This evaluation aimed to identify nodes that were of the highest importance to patients and which could make a statement about the quality of oncological care being provided. The evaluation displayed how positively or negatively each patient evaluated the individual nodes in each interview question.

Excerpt from: Table 72: Node Evaluation With and Without ASC -3+3

with	K	appre	ciation o	doctor	- staff										S = Su	m ato	o j
ASV	N	Grade	1 to 3:	-3 =	poor	2= mod	erate	+3= go	od								
PatId. I to X	к	1a	1b	1c	1d	1e	<b>1</b> f	1g	1h	11	1j	1k	11	1m	1n	10	5
XI EW	N	3															3
XII FG	K	1a	1b	1c	1d	1e	1f	1g	1h	1i	1j	1k	11	1m	1n	10	
	N			3	3	3	3	3	3	3	3	3	3		3		3
XIII FHJ		1a	1b	1c	1d	1e	1f	1g	1h	1i	1j	1k	11	1m	1n	10	
	N						3	3	3	3			3			3	18

The evaluation, presented in a graph, displays both groups of 10 patients, all 15 interview questions from a-o and all 31 nodes which were created individually. A grading scale developed by the researcher was applied to the results of the interviews that ranged from - 3 to +3 and stands for the intensity of characteristics and dimensions. Patients who reacted particularly negatively to specific nodes or questions were assigned a grade of -3. An example of this is patient GB's reaction to question "I":

TABLE 17: INTERVIEW ANSWER (GB)

GB:

I: "How much have you been included in the decision-making-process and the therapy?"

"I Feel not so ... well, ok, but at the beginning, when the cancer came back, I wanted more ...to talk to .... I did not know all about, but felt irritated. Chemotherapy was the only option, I felt depressed. The examination, I did not know what it was all about, ... suddenly the results were clear, cancer was back again".

The researcher highlighted the following code words in the statement: "lack of assistance and support from the physician, patient utters concerns and worries, feels that he does not have enough time, lacks information about diagnosis and treatment, personal stress". These negative responses resulted in the answer being assigned a grade of -3.

Those who reacted positively to a specific node or question were given a grade of +3. An example of this was patient NJ's response to question "I":

### TABLE 18: INTERVIEW ANSWER (NJ)

### I: "How much have you been included in the decision-making-process and the therapy?"

NJ:

"Well, I will become healthy again, I put my trust in you 100 % for my life and my treatment. I know I have no alternative and chemotherapy is my only option but I look in the very first moment in your eyes and say to me: I trust you!"

The researcher identified the following code words in the statement: "trust in the doctor, hope, appropriate treatment, information about treatment, continuity of support, fighting against cancer, transparency and information". The positivity of patient NJ's answer resulted in the answer being awarded a grade of +3 by the researcher.

These drastically different answers to the same question reflect the differences in perspective of different patients. The first patient felt obliged to adapt, seeing no way of changing his situation. The second patient felt positive about the treatment process. A grade of 0 was given to answers not related to the question, and a grade of 2 was assigned when a patient provided an irrelevant answer. An example of this was patient TA's answer to question "c":

### TABLE 19: INTERVIEW ANSWER (TA)

### Question c): "What are your main concerns and fears relating to your situation?"

TA:

"Everything is ok at home. My son works for the country commissioner but.. first.. he was not so good in school .... but now, when I need something....He knows his stuff".

The researcher repeated the question a second time, but the interviewee was not able to answer in a way that related to the question. For this reason, no code words could be assigned. A grade of 2 was assigned to the code words "needs no psychological support" and "personal conflicts unrelated to the medical practice". Because the interviews were presented in a flexible format, references to individual nodes were sometimes made multiple times in different questions. This is taken into account in the table; a grade is assigned each time that a node is mentioned, no matter which questions the topic comes up in or how many times it has already been mentioned.

This, of course, leads to the possibility of a research limitation. How the patients answered the questions could have affected the number of points that they were

assigned. More talkative patients likely acquired more points than patients who said less but had equally positive or negative impressions of their outpatient experience. The higher aim of the node evaluation was to determine how relevant the individual nodes are for the oncological quality of care in the sense of Donabedian's (1980) structure and process parameters.

## 4.4.3 Original table

The table below henceforth referred to as the "original table" shows how favourably each patient evaluated the individual nodes and sub-nodes. The original table also provides a sum of all the nodes. The colours in the table (e.g. original table, see Table 74 in the Appendix chapter) represent the word categories that came up most frequently in the interviews, and the lines show the causal relationship to the chosen categories. The visualisation provides a significant overview of the qualitative interview results. This conceptualisation was based on the results of the first coding process after the evaluation of nodes (good, intermediate, or poor).

TABLE 20: EXCERPT FROM THE ORIGINAL TABLE

Subnode	e diag	gram	eval	uatio	n wi	thou	t AS\	/								
	"go	od"	: hig	h co	unts						"po	oor"	: low	/ cou	ints	
without	ASC	Valu	ıtatio	n-sur	ns											
ID	ad 1	ad 2	ad 3	ad 4	ad 5	ad 6	ad 7	ad 8	ad 9	ad 10	ad 11	ad 12	ad 13	ad 14	ad 15	ad 16
I AK	12	12	2	6	5	6	18	9	9	-5	6	17	6	12	3	11
II EW	0	-4	-8	6	3	6	0	2	-3	1	0	9	0	3	0	5
III HD	8	11	4	3	3	20	17	6	5	-6	6	24	0	0	8	8
IV KU	3	9	2	3	4	6	4	3	2	12	8	27	0	6	12	0
V NJ	9	16	12	5	14	13	12	9	5	15	9	24	6	6	6	9
VI SG	12	3	14	13	12	15	14	16	17	20	12	17	5	3	6	8
VII SB	11	5	1	7	9	24	12	9	12	26	12	32	6	18	12	7
VIII SH	2	2	6	-1	11	16	6	2	15	25	7	11	-1	7	2	12
IX TA	3	13	3	7	9	17	6	23	2	24	9	18	3	6	12	9
X PR	11	18	7	12	12	11	12	12	14	16	7	29	3	0	6	11
Total/uk	71	85	43	61	82	134	101	91	78	128	76	211	28	61	67	80

In this table, the rows depict the highest and lowest sums of each patient, and the columns present the highest and lowest sums of each node. The point of this is to present how positively or negatively each patient voted in total:

(e.g. without ASC: EW: 61 + SB: 379 points, with ASV: FG: 366 + KI: 145 points). The second aim of the table is to demonstrate how positively or negatively each node was voted: (e.g. without ASC: sub-node 12 with 211 + sub-node 23 with 17

points; with ASC: sub-node 12 with 184 + sub-node 31 with 20 points). Of course, a group of nodes that is neither high nor low is featured in the table. This will be considered later.

Two of these tables were created: one for the ASC group and one for the group that did not receive care under the ASC model. The group without ASC was shown to have a higher rate of patient satisfaction with a total sum of 2722 points, as compared to 2313 points in the ASC group. A limitation of this step could be that the total sum does not represent the thematic specificity of the questions (see Table 73, Table 74 and Table 75).

In a second step of the analysis process, the three to seven patients who had the highest overall amount of points and the three to seven patients who had the lowest overall amount of points were identified. The original aim was to create groups of four patients; but in order to create groups with similar total sums, the group sizes needed to be adapted. Once formed, these groups of three to seven patients were compared. The comparison looked at the individual node ratings in both groups, seeking to identify patterns on how patients rated different nodes. In the group with the most overall points, the individual nodes that were especially positively rated (so, awarded with many points) were identified. Likewise, in the group with the least overall points, the nodes that were particularly negatively rated (so, given the least amount of points) were highlighted. Once this was done, the researcher observed how often the patients corresponded in terms of their point allocation. If the same node was highlighted as being especially good or bad by several different patients, this constituted an "intersection".

In a process known as "intersection-grading", these intersections were each assigned a grade, the scale of which was once again of the researcher's own devising. If, e.g. 4/7 or 4/6 of the chosen participants gave a high grade to a specific node, they were assigned 2 points. If, e.g. 4/5 or 4/4 voted similarly, they were respectively given 3 and 4 points. The group with high grades were assigned to the category "good or positive", and the group with low grades were assigned to the group "bad or negative". The purpose of these comparisons was to evaluate the nodes further. The large number of "good" and "bad" node intersections are of great importance for the validation of the oncological quality of care in the unit.

### 4.4.4 Cross diagram

The third step in the analytic process was to create "a cross diagram" (Table 76 and Table 78). The grades of intersections between the 28 nodes are listed in the cross diagram. From these intersection grades, the total sum of points of each node was determined. Cross-diagrams for "good" and "bad" intersections in both

groups were created. The diagram aimed to shed light on the relevance of the "good and bad" intersection-grades and the frequency with which groups of patients voted for specific nodes. Particular attention was given to voting patterns, and the amount of intersection (for "good" and for "bad"). A limitation is the breadth of the results of the cross graph and the small number of patients.

### 4.4.5 Sort tables

A <u>sorting table</u> (see Table 80, Table 81) was created to help filter and sort the results from the original table and the cross diagram. The total sum of nodes from <u>the original table</u> was sorted in descending order. The sorting table is divided into three fields (A-C). The total sum of nodes from <u>the cross diagram</u> was sorted in descending order. The 10 nodes with the highest sums were assigned to field A, the 10 nodes with the lowest sums assigned to field C and the middle to field B. A goal here was to shed light on fields A and C to build clusters of nodes and to find meta-themes, or so-called "families" to see how relevant the "family-clusternode" is for the oncological quality of care.

This table sorts nodes by their scores from left (field A) to right (field C) and sorts patients by their total personal scores top-down in descending order. Interestingly, the patients both with and without ASC with the highest total scores in fields A and C rated better than those with the lowest scores by a ratio of approximately 3:2. Also interesting is field C, which has particularly low intersection grades. There are numerous single questions with explicitly higher evaluation points. This observation will be considered in section 5.1.4 data synthesis. All sort tables from the original and cross diagram are in 11 Appendix C: Methods. See Table 82: Sort table major comparison (with and without ASC).

# 4.4.5.1 Sort table comparison of sorted original and cross table with and without ASC

This table compares all A and C fields from the original tables and cross-diagrams from both the ASC and non-ASC group. These comparisons lead to nine combinations in total, i.e. this table presents an overview of the concordant and discordant nodes of the nine combinations for fields A, B, and C of the original and cross-diagrams (see Table 84: Sort table between original and cross diagram in the Appendix chapter method B). The corresponding, concordant nodes are marked with symbols and blue lines for field A in the upper part of the table and brown lines for field C in the lower part, and yellow lines to the nodes in the middle field B. The red dotted lines and arrows indicate particularly discordant nodes that do not correspond.

The overview of this intersection table shows how many of the nodes from fields A, B and C, both with and without ASC simultaneously reoccurred in the nine combination nodes in field A of the cross diagram with intersections for "good", for example. It will be compared to which nodes from field A can be found in both groups in the relevant cross diagram. In particular, the goal is to determine these nodes that frequently build intersections in fields A or C (see Appendix C: Methods, Table 84).

### 4.4.6 Question-evaluation-table

In the fourth and final step, the <u>question-evaluation-table</u> (Table 85: Question evaluation original table) from step 1 was combined with the node evaluation from the interviews and the node evaluation from fields A and C. Once again, two tables were created for this step – one for the original table and one for the cross diagram for both groups. It will be examined how many scores the questions from "a to o" obtained in the nodes of the respective field A or C and juxtaposed against one another in both ASC groups.

The total sum of the sub-nodes created in table 1 and the highest nodes from field A (e.g. 2, 9, 19, 1, 11) were placed in a table and sorted by question (from a-o). The aim here was to compare the interview questions from field A with C to find characteristic features that explain the similarities or differences between the fields and the patients and the nodes (Triangulation). The researcher sought to identify the interview questions that were given high or low evaluations by the patients to see concordance or discrepancies.

A good correlation between the fields and between the patient groups is a marker for regularities and typical features of the sub-nodes to differentiate field A and C. The question-evaluation sum "bad" was omitted because the group of patients with lower scores will often find themselves in other nodes with lower scores. This was mostly because some patients avoided answering specific questions, leading to a grade of "null" in the point allocation. In these cases, a question evaluation sum could not be calculated. The following chapter, 5 Findings data synthesis, will explain what these results indicate for the original and cross diagram (5.1.4.1 und 5.1.4.2)

### 4.4.7 Questionnaire Analysis

The questionnaire analysis focuses on three main categories of health: physical, psychological and pain-related issues. The questions asked were either yes- or noquestions or questions where a patient rated a satisfying experience according to the following scale: very good – good – mean – insufficient - poor – very poor.

In the following paragraph, the researcher explains details of the SF-12 measurements and the implementation and evaluation of the chosen questionnaire.

## 4.4.7.1 Standardised short-form-(SF-12) questionnaire

The SF-12 is one of the well-established generic instruments used to collect psychometric validated assessment parameters (see Figure 12). In previous medical studies, the SF-36 (36 items) and later SF-12 (12 items) surveys have offered an advantage over other QOL measurements because of their ability to measure medical outcomes (Bullinger et al., 1995; Ware et al., 1995). As these researchers state, this is another advantage of the SF-12 survey – medical outcomes very often impact the quality of life. Good quality of life consists of physical and psychological well-being and can be evaluated with QOL and PS surveys. The impacts of illness and treatment on subjective health and the health-related quality of life of patients are of growing interest in clinical studies (Mays & Pope, 2000). Researchers now see the value in studying such factors rather than focusing uniquely on mortality (Huebner et al., 2014). The interviewees need to provide information by themselves about their state of health and their functionality. The 12 items of the analogous SF-12 questionnaire include physical, psychological and pain scales, social and role functioning. A detailed description of the implementation of the SF-12 analogous questionnaire follows (see also Table 68: Questionnaire with own comments)

### Implementation of the questionnaire

The questioning was conducted from August until December 2016 with group I and from January until March 2017 with group II. The ten participants in group I were not being treated under the ASC model. In group II, all 10 participants were undergoing the new health care model. The questionnaire was handed out two weeks after the conducted interview and was completed by the participants. All participants had received chemotherapy for at least two months and suffered from severe and incurable gastrointestinal cancer. (Basic requirements and part of the inclusion criteria for all participants).

A fixed interview and questionnaire appointment were determined for every participant. The interviewee chose the time that suited him/her best and was therefore not put under any time pressure. The interview and questioning were conducted in a relaxed and comfortable atmosphere. A private room within the practice was dedicated to the purpose of conducting the interviews.

## Demographic data

It is important to explain why demographic data was collected in this study. Carr and Higginson (2001) stated that the health-related QOL when measured by the expectations and experiences of participants, is based on personal opinions that were developed during the patient's lifetime and on social demographic influences. Individual factors that influence a patient during illness and treatment can change a patient's expectations. Therefore, QOL data cannot be interpreted without considering time measurement. To draw main conclusions based on the collected social demographic data such as the age, gender, family status, distance away from the practice of the patients was not possible. The different sample size was too small, and the selection not representative. This case study consisted of two groups, each of ten participants. The age of the participants in the first group ranged from 53 to 78. In the second group, the age ranged from 63 to 83. One female participant was in the first group. The second group contained four female participants. Most participants were retired and lived an average of 20 km away from the medical outpatient unit. These details were recorded for each patient and were structured in a table (see Table 70). Also, the researcher focuses on equal conditions for the patients despite the heterogeneity of the group.

### The decision for the chosen questionnaire type

This questionnaire was developed analogous to the SF-12 and was useful because the respondents were asked to provide a global rating of their overall satisfaction with their actual state of health and their physical ability in every-day life during the past four weeks. This information was pertinent to the research aim of obtaining information about the patient's current QOL. Bredart et al. (2001b) argued that QOL for oncological patients has become an increasingly significant comprehensive parameter for physical, psychological and pain issues.

The chosen questionnaire was modified analogous to the presented SF-12 questionnaire in Germany and included five categories: physical performance, psychological well-being and pain, social life and role functioning. To enable a qualitative evaluation, the answers of the SF-12 were allocated and valued concerning the mentioned first three categories. Answers that contained aspects of social life and role functioning were also allocated to the three categories. Occasionally, a few questions and answers appeared in several categories at the same time. In general, the SF-12 was measured by a Likert scale, a psychometric scale which covers the intensity of agreement on a range from:

 A three-point scale format including, e.g. limited a lot, limited a little, or not limited at all related to physical activity and role functioning questions.

- A five-point scale format including, e.g. strongly disagree (1), disagree (2), neither agree nor disagree/neutral (3), agree (4), and strongly agree (5) related to pain; additionally, overall health is reported from excellent to poor.
- A six-point scale, e.g. all the time to none of the time, assessing the category of social functioning, vitality and mental health.
- The Likert scale is the sum of the questionnaire responses of the Likert items.

The SF-12 questionnaire was chosen because it addresses some of these topics. A disadvantage of the SF-12, however, is that some questions cannot be easily answered in a survey context. Factors such as pain are often complex and cannot be easily described in a short-form survey. Often, patients themselves do not know how to explain how well they are doing in terms of physical functioning (Wilson & Cleary, 1995). Additional questions or further requests for clarification cannot be asked of the respondents in a short-form survey. The interviewer has no chance to respond to questions from the interviewee and no opportunity to form an impression of the participants or of their situations.

## Assessment construction

The questionnaire was answered with either (Yes=0=bad/No=1=good) or a rating ranging from poor to good (0=poor and 5=very good). Every category (physical, psychological, pain) was linked with a number, as shown in Table 88: Questionnaire assessment table without ASC in Appendix C Methods.

A clear allocation was achieved relating to 9 items (1, 2, 3, 4, 6, 9, 10, 11, 12) in the category physical functioning (e.g., How would you describe your general state of health?); 5 items (5, 6, 9, 10, 12) in the category psychological functioning (e.g., Regarding your mental state during the last four weeks: Have you suffered from depression or fear?) and 3 items (7, 8, 12) in the category pain (e.g., How strong (infer) were your pain symptoms in the last four weeks?). Respondents were asked to complete their questionnaire two weeks after the face-to-face interview. In total, 20 participants completed 20 questionnaires. The generated data of the questionnaire was not significant for testing because of the small sample size. No pretest was necessary for the questionnaire because of the similarities between the questionnaire topics and the interview questions.

### Description and implementation of the questionnaire analysis

The questionnaire design stemmed from an adaption of the original SF-12 standardised questionnaire. The first items in the questionnaire pertained to physical functioning and included general health condition and everyday functionality.

These items are defined and formulated in the full survey below (see Figure 12: Questionnaire SF-12 with items and in Appendix C Methods).

The original standardised questionnaire SF-12 included combined data from 12 questions with different answer options and the attaining number of points. Additionally, the lowest and highest points are not distributed equally, namely a good rating is high or low valued. A retrospective renewed evaluation takes place: that means unfavourably-bad with the lowest point and especially good with the highest points to evaluate the SF-12 questionnaire in relation to the interview questions. This relates to questions 4, 5, 12 and assessed questions in role functioning (category physical and emotional health). The other questions are valued analogous to the Likert scale with a maximum of 3, 5, and 6 points per answer. Therefore, the questions obtain a very different total sum of points from 5 up to 39 points. As mentioned before, all questions were summarised and assigned to three categories. Some questions could be classified into several categories, e.g. question 12, with an overall answer option of 39 categorised into these three categories (Table 87). To make the different scales of the answers comparable, the researcher performed a different evaluation from 0 to 4 points of the Likert scaled questions. The total sum of points of the questions was put at a level of 100 %. In each case, the individual obtained total sum of points was expressed as a percentage.

Finally, all answers of each patient and category have been added in three columns as a percentage (the maximum achievable sum is 100 % of each category and reflecting the highest level of quality of life). The formats of the instruments used in this research differ in significant ways. It is important to distinguish between the chosen data generation methods. Quantitative data collection methods are based mostly on measured numeric factors (Blaikie, 2009). In this qualitative research, the result from the quantitative questionnaire is shown on a scale for comparative purposes. The scale corresponded to the research questions posed at the beginning of the research and did not bias the results. That means the use of an analytical framework that organised the questions and answers into the three categories (physical, pain, and psychological) support answering the research questions. Previously, a clear allocation of categories was assigned and scaled on the first column physical well-being, second pain and third psychological well-being. Subsequently, a bar graph, (Figure 10: Questionnaire comparison WITH interviews (-ASC)) shows the questionnaire results from 20 participants with and without ASC for the three categories. Moreover, the researcher uses an effective method to quantify the generated qualitative data to gain relevant information from subjective interpretation by thematic analysis. Through the process of assigning the results to the three categories of pain, psychological and physical aspects, the questionnaire can be evaluated qualitatively.

# Evaluation of the chosen questionnaire

In total, the questionnaire included nine physical, six psychological and three pain items. The result of the survey was the sum of all scale ratings of each of the three categories. After reading the data, the researcher groups the data into the three-item categories, the so-called themes (pain, physical, psychological functionality). The themes should describe the main points the respondents expressed in the questionnaires. These items are defined and formulated in the full survey below (see Table 88).

For the intro- and inter-individual qualitative comparison of the three categories, a dimension scale was defined (physical, psychological, painless table question-naire evaluation in comparison with interviews), (see TABLE 69: Questionnaire evaluation in comparison with interviews per patient). Scaling questions fit into qualitative research due to certain aspects: they are better conveyed through words and cannot directly be observed in numerical form (Morse, 1991).

# The importance of QOC in the health care sector and why the research leads to a weighting of the relevant codes.

The evaluation of PS and the valuation of medical treatment from the patient's perspective has gained more and more importance in recent years. The topic is also relevant for supply management and quality assurance. Since the introduction of health service reform (§135a) in 1989 (Health Care Reform Act) and 1993 (Health Care Structure Reform Act) in Germany, quality assurance has been mandatory by law. Mandatory means all medical caregivers have to fulfil the requirements of inter-institutional quality, based on fixed quality standards. §137 was precisely for quality assurance and applies to both in- and out-patient care.

A useful definition of quality according to quality standard DIN EN ISO 9004 is the relation between realised (achieved) and required (demanded) quality (Donabedian, 1966). Donabedian (1966) designated quality in health care in structure-process-outcome parameters. Quality is multidimensional and not directly quantifiable but can be described with various indicators (Nübling et al., 2007).

In medicine, the outcome is one of the most important aspects of quality, and the vast majority of chosen indicators in studies represent therapeutic perspectives (Bredart, Razavi, & Robertson, 2001a). As Bredart et al. (2001a) stated, patient orientation (involving patient activities, the needs and expectations of patients) in health care was focused as a final dimension of quality in their study. Quality can be assessed externally or by an individual medical institution with so-called quality indicators which must be objective, measurable, identifiable and the relative weighting in order of importance appropriate to improve supply structures

(Valdes-Stauber, 2005). Data collection methods include standardised questionnaires, e.g. short-form-36 questionnaire, Cella and Tulsky (1993)'s Functional Assessment of Cancer Therapy - FACT questionnaire or the EORTC international validated questionnaire. A drawback of these assessments is that they only collect data from the point of view of the medical provider rather than that of the patient. Rentrop, Böhm, and Kissling (1999) took subjective patient impressions into consideration and stated that individual PS provides both feedback for the medical practice and is a targeted indicator for the quality of service, supply and treatment. Möller-Leimkühler et al. (2002) emphasised that increasing the role played by patients when it comes to therapy organisation leads to better compliance on the part of the patients and consequently, more effective treatments. According to Rentrop et al. (1999), PS, like health status, is an outcome indicator of medical treatment and a relevant endpoint for acceptance of treatment. More precisely, patient evaluations of the treatment and supportive care made available to them could be a criterion for distinguishing whether the patient has received adequate treatment. This is only the case if perceptions, expectations and existing prejudices do not influence the patient. Möller-Leimkühler et al. (2002) argued that PS depends on patient expectations and is a process of adaptation. PS is influenced more by subjective than objective factors. Patients tend to adapt to a given situation which they cannot influence. As Möller-Leimkühler et al. (2002) pointed out, resignation is also a part of PS because patients are at the mercy of the institutional services that they cannot actively change or influence.

To conclude, QOL and PS are individual constructs. PS is multidimensional. One key element of PS is patient orientation. The patient's perspective is important for quality management concepts. PS consists of cognitive evaluation and an emotional reaction to structure-process-outcomes of provided services. Many widely used quantitative standardised questionnaires measure some aspects of a patient's life but are not individual patient-centred. They do not weight topics differently depending on the patient.

From both paradigm traditions as resources for thinking, the researcher shows that the quality of qualitative research is improved by using numbers, and the quality of quantitative research is improved by consideration to behaviour and interpretation at all stages. The components of QOC depend on the subjective experience of patients, interpersonal, medical and organisational processes. The questionnaires and detailed interview questions adopted by this research consider the multidimensionality of PS and QOL processes. There is a need in medical research for an exemplary PS assessment. This assessment could be compared with an easy, quick, but similarly multidimensional standardised survey that also in-

cludes similar questions as the interview survey. This could be used to draw immediate conclusions about QOC and potential quality improvements. The purpose of the present research is to - in a pilot qualitative study - examine whether PS and QOL can be used to evaluate the QOC in an outpatient practice. In contrast to other surveys with randomised large samples, the present research was performed in an outpatient unit with a small sample size. The study was therefore practicable, efficient and feasible. The results of the research could be beneficial for patients and could be used for quality improvement in medical practices.

### 4.4.8 Comparison between interview and questionnaire

The interview results were compared and contrasted with the questionnaire (see TABLE 69: Questionnaire evaluation in comparison with interviews per patient) and sorted with the highest sum of the interview in descending order of the sums of the questionnaire. To make them comparable and to show the differences, the researcher adopted a percentage system to see if there are significant discrepancies between QOL and PS.

The interview and questionnaire were chosen based on the PASQOC study to form broad conclusions related to QOL, PS, QM and QOC. While the questions were derived from the PASCQOC questionnaire, they were adjusted to focus specifically on the researcher's interests. The interview questions were organised in four question-blocks. In total, there were 15 questions, lettered a-o (see Table 63 to Table 67). Questions a-c were related to the general condition, hopes and concerns of the patients. Questions d-g were questions related to internal aspects. Patient medical information was addressed in questions h-k, and organisational aspects like the accessibility of care and treatment environment were the topic of questions l-o.

The answers to the questions were assigned to the so-called nodes. The main nodes were closely related to interpersonal, medical and organisational aspects of the outpatient unit. However, patients often answered in a way that avoided the issues or were contradictory. Consequently, it was not possible to classify answers into neat, distinct categories. It was challenging to evaluate the responses. The researcher consistently interpreted and evaluated patients' answers by taking into account the personal issues and the treatment processes of the patients. This approach was inspired by Kuckartz's (2007) qualitative content analysis. Cases and categories structured the generated data material from the interviews. Cases refer here to the 20 participants; categories to the themes from the interviews were classified into main nodes and sub-nodes. This structuring resulted in a qualitative matrix-based theme table. The relevant parts of the interview text passages made

up the rows and columns of the matrix table. This organisation was chosen because it allowed the researcher to dissect the findings and to draw conclusions without losing sight of the context formed by the patient's answer to the question. This matrix also allowed the researcher to build case and node classifications both with vertical and horizontal alignments. Such a matrix was also chosen because it made it possible to compare and contrast multiple rows and identify patterns. The patterns identified in groups of participants could be concentrated into metathemes. Attention was paid to the qualitative content analysis idea of "typical textual understanding". A systematic scientific method was followed with a structured and rule-governed procedure that applied quality criteria. In this case, "systematic" means that the complete coding process was conducted with the support of NVIVO software. It is important to clarify that the data guided the researcher and not the NVIVO software. In qualitative research, the researcher generates, analyses and synthesises data without the use of the software.

# Summary of data analysis methods

The analytic process will be briefly described to provide a better overview. In consideration of the principles of social constructivism and for reduction of bias, the answers of the participants to particular interview questions are allocated and validated to the 31 thematic nodes to gain more understanding and knowledge. The degree of suitability, agreement and disagreement of interview questions is validated on a scale from -3 up to +3 (see table 76). The 31 thematic nodes represent a comprehensive and detailed description of the QOC. The in-depth analyses point out which of the thematic nodes are particularly important and representative for the QOC.

The validation of a node may be influenced by the thematic content of the node, the real quality of the unit, the individual behaviour and perception of the interviewee or accidentally based on the minimal number of participants. A numerical sorting for the total amount of points of nodes (see table 77) and the sorting of intersections of nodes with regard to good and bad validations from patients is performed to address this problem (see table 78-85). After that, regarding a higher or lower sum and a higher intersection rate for good and bad validation, the in tabular form sorted nodes were compared between both groups with and without ASC (constant comparison, see table 86 and 87).

Through this, the nodes should be identified that are particularly well validated and simultaneously are intersected for good and/or bad validation and, therefore, especially significant and relevant for the evaluation of the QOC. In addition to this, the researcher performs a comparison of these nodes between both groups with and without ASC. Only these nodes that provide the same attributes for both

groups with and without ASC were supposed to be reproducible and relevant for the QOC, (see table 88).

For confirmation of the results, the nodes were compared and cross-checked with similar questions (see table 89 and 90). Then follows a comparison with the results of the quantitative reference study PASQOC, which had the same goal to examine the oncological quality of care, as mentioned earlier. Finally, the results of the qualitative analyses of the interviews are juxtaposed and interpreted with the results of the qualitative analyses of the SF-12 analogous QOL questionnaires (see table 91-96).

After this summarised overview, a more generalised consideration follows.

A single case study can provide new insights into common attributes or patterns that occur throughout the research process. As Almutairi, Gardner, and McCarthy (2014) state, pattern-matching includes comparing two or more patterns to see if there are differences or similarities which are compatible with the observed behaviours. The researcher discussed the pattern technique as one possible method in a case study approach; but from the researcher's point of view, pattern-matching is difficult to implement and confusing for an inexperienced researcher.

This research looks at attributes that may be responsible for similarities and differences of the so-called nodes - which may occur or not in one or the other of the two groups. Through triangulation (see question-evaluation-table) these nodes were compared; data from the questionnaires confirmed interview statement results. As Goodrick (2014) suggested, at the heart of a comparative case study approach is the comparison within the case. Yin (2009) argued that a comparative case (CC) approach inspires new questions, as new questions are needed to explain the discovered patterns and relationships. In this way, the answers to the causal questions can be examined, and main patterns can be identified and consequently either be included or ruled out.

In this research, the described attributes of the nodes and sub-nodes were compared with the highest or lowest level of answers of the questions in the interviews as well as the weakest or strongest answers from the questionnaire. As Garratt et al. (2002) explain, it is helpful to use a summary table (the so-called original table) for the most important keywords and attributes in the case. To better understand what possibly might influence the survey and how better to align the survey to the specific research project to achieve the expected outcome, the key is interpreting how several factors influence or provide insights or relationships among combinations in the preliminarily-raised research questions. At the end is an understanding

and interpretation of these factors to see if all coding, dissecting, can build a picture and can answer questions. The next step in chapter 5 Findings is the other specialised characteristics from the interview results.

# 5. Findings

This research carried out a qualitative case study design that generated data from interviews and questionnaires. The research sought out structure-process-outcome parameters of QOC in a single oncological outpatient unit. The medical outcome for severely ill patients refers to a longer life with good PS and QOL. The medical outcome is the sum of hard endpoints such as tumour response rate, side effects of therapy and prolongation of life and soft endpoints such as QOL and PS. These QOL and PS parameters consist of physical, psychosocial and emotional well-being aspects which, as demonstrated in the preceding paragraphs, can be evaluated through interviews and questionnaires.

The first objective of this research was to determine to what degree a qualitative method that evaluates QOL and PS can be used to evaluate the oncological QOC in a single outpatient unit. A second objective was to see how the new ASC health care model impacts the QOC of patients.

The purpose of this research was twofold. On the one hand, the research aimed to compare interview data about PS with QOL data obtained in the questionnaires. This comparison sought to gain an understanding of patient perspectives and the patient experience of health care. On the other hand, the research aimed to conclude about the oncological quality of care of patients. By evaluating satisfaction with the service provided, the research sought to identify patient expectations and determine how the new ASC supply model is beneficial for patients.

The results of Kleeberg et al. 's (2005) PASQOC study suggest that QOL and PS are favourably influenced when a good medical outcome is achieved. Bredart et al., (2015), Bullinger (2016), Ware et al. (1978) and other researchers have comprehensively examined these parameters in large, multicentre, quantitative studies. The results of these extensive quantitative studies, however, cannot be reproduced in small studies that focus quantitatively on a single outpatient unit with a small sample of patients. This is because the illnesses and personal needs of oncological patients have very diverse characteristics and there is far too small a sample size in a single outpatient unit to come to any significant conclusions about these different heterogeneous characteristics.

The data analysis chapter presented the chosen methods for data processing. The aim of this chapter is to determine whether they were useful and practical and to present the final outcomes of this research. Concluding with statistical data

analysis is not typical for a qualitative approach. The results of a qualitative approach are interpretative. In quantitative studies, the typical quality criteria are validity and reliability. Qualitative studies, on the other hand, focus additionally on other factors like trustworthiness, credibility, dependability and conformability. The researcher was especially thorough when processing the results of the study to take these quality criteria into account. This involved constantly comparing the interviews and questionnaires. The two types of generated data (interview data and questionnaire data) were combined using a system developed by the researcher. The problem of having to incorporate numerical scores from the questionnaire into a qualitative study is discussed in this section. This issue is considered in the parts of the thesis devoted to data synthesis.

The following chapter presents the key findings derived from the interviews and questionnaires. The relationship between QOL and PS is examined to evaluate QOC.

# 5.1 Data synthesis

The findings chapter concludes on the QOC in a single outpatient unit based on observations of the QOL and PS of two groups of participants. The coded data obtained from interviews were compared and sorted with one another to form an overview for whether there are similarities and differences. 'Surprising' or unsuspected data regarding patient experiences in the outpatient unit was also noted. As Bazeley (2009) points out, comparison leads to further questions and to an appreciation of the depth of an investigation. The theme-related analysis of the coded data in this thesis brought meaningful relationships between two sets of codes to attention. An NVIVO coding query was used to identify comparisons between QOL and PS. Matrix coding, also a function of NVIVO, was used to compare what the participants in groups with and without ASC said about their experiences. Furthermore, an NVIVO group search query was performed to obtain information regarding the specific attributes and demographic data of the patients.

The twenty transcribed and coded interviews were analysed together with the twenty questionnaires. A comparison of the interviews and questionnaires in the two groups revealed that specific topics were of greater personal relevance to patients than expected.

# 5.1.1 Comparability of the two groups with and without ASC

The ASC and non-ASC groups being compared were subject to the same inclusion criteria and continuity of treating team outpatient unit. All patients were over 18

years old with severe gastrointestinal tumour diseases. Patients had been undergoing oncological treatment for at least two months. Members of the ASC group had to be willing to confirm that they consented to participate under the conditions of the new health care model. An in-depth description of the inclusion criteria is provided in section 1.5 Influencing factors.

The main differences between the old health care model based on the oncology contract and the new ASC health care model are depicted in the literature review (see TABLE 1: Comparison of ASC and oncology contract). The outpatient unit being studied worked under the oncology contract model until the introduction of ASC and included essential points from the new health care model ASC. The researcher had the opportunity during the study to get to know patients' everyday practice and was involved in their medical routines. The new and relevant innovations of ASC are listed in the following section, accompanied by the comments and considerations of the researcher (in italics).

Patients participating in the ASC model are provided with extensive information about the structures and services that are on offer to them. Patients must sign a written declaration to be cared for under the ASC model. Patients do not have to provide consent when receiving care under the oncology contract model.

By explicitly agreeing to be treated under the ASC model, patients join a system that provides them with comprehensive information regarding their disease and treatment options. For that reason, that led the patients to an intense confrontation with the illness and treatment options.

This confrontation with illness could not be avoided. However, patients are also confronted with the effects of their illnesses while living their everyday lives. The interview provided a controlled environment in which patients could explore the effects of their diseases with understanding healthcare experts. In the interviews, it was inevitable that the patients be forced to confront their diagnoses and illnesses. However, patients in oncology are used to communicating in everyday life about the burdens and pain posed by their tumour diseases. In this research project, patients could discuss their illnesses under controlled conditions.

 Under the ASC model, patients are treated by an interdisciplinary team of specialists. The doctors that make up this team are not interchangeable. This means that each treating specialist is personally familiar with the individual patient's background.

The oncology contract had fewer specialists in every team. That said, the process of treating patients has not significantly changed under ASC. It is unclear what roles are played by general practitioners, healthcare professionals and patient relatives under the ASC model.

3. It is a rule that their ASC team only treats patients being treated under the ASC model of specialists.

None of the participants in this study needed to access specialist practitioners on the ASC team other than the oncologist. This could reflect the medical care provided in the outpatient unit. A limitation of ASC is that patients must live within 30 minutes of their treating specialists. This could prove problematic in rural areas.

- 4. Under ASC, the treating physicians hold tumour boards and conferences weekly. As abovementioned, specialists from a broad range of disciplines attend these meetings (e.g. ear-nose-throat doctors, nephrologists). The weekly interdisciplinary tumour board delivers no visible additional information for doctors or patients in most scenarios as under the previous oncology contract model. It is also unclear who covers the costs of these meetings and who is responsible for questions of liability.
- 5. Under ASC, office hours are provided for patients every week at the offices of the ASC team leader. Under the oncology contract, specific office hours were not provided but treating doctors were available by telephone on a 24-hour basis.

None of the participants of this study showed any desire to book appointments at the offices of the ASC team leader.

6. Treating ASC specialists are obliged to provide detailed documentation of their work.

Doctors treating patients under the oncology contract were also obliged to provide thorough documentation. Both groups of patients in this study received folders with regularly updated information about medical treatment and therapy. It is unclear precisely what needs to be documented under the ASC model. The oncology contract, however required that doctors provide documentation about measurable patient endpoints such as mobility, ASC does not require doctors to record patient endpoints.

7. ASC provides extra services not covered by the oncology contract such as PET-CT examinations, auxiliary materials such as speech therapy and other, non-medical forms of treatment.

In this study, auxiliary materials and other non-medical forms of treatment (e.g. physiotherapy) were not necessary for the patients involved and were therefore not used.

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8. ASC works with self-help groups to ensure that patients have as much support as possible. either ASC nor the oncology contract organises aftercare for tumour patients.

In this study, no patients participated in self-help-groups during the treatment process.

In this study, the patients that transitioned to the ASC system experienced slight change in their daily care. Patients took advantage of fewer ASC benefits than the researcher of this study had expected. This meant that the chances of detecting differences between the ASC and non-ASC groups decreased. On the other hand, this meant that it was easier to see the context between the interview and questionnaire data of the two groups. In the following paragraphs, the researcher outlines the findings of the gathered data.

### 5.1.2 Interview questions

For the research design of this qualitative study, the researcher selected a semistructured interview combined with a questionnaire analogous to the concept of the quantitative PASQOC study. Contrarily, this study considers the qualitative analysis of the QOL questionnaire. A critical reflection from the researcher is the subjective interpretative evaluation of the interview questions based on the valuation systems of the researcher. Therefore, the researcher implemented the quality criteria of qualitative science that are also described in the literature by Frommer (1998). Frommer (1998) states the importance of quality assurance criteria of medical treatment, the value of different research approaches and the evaluation of the success of treatment (see also Daly et al.'s (2007) hierarchy of evidence for assessing qualitative healthcare research). In consideration of these quality criteria, the researcher aimed to answer the research questions by her developed rating system. The mentioned rating scores of interview responses were assigned to the corresponding nodes. In the following excerpt, the researcher shows interview examples to explain her decision for the subjective interpretation and weighting of nodes.

TABLE 21: INTERVIEW ANSWER (KU)

Question i): "How much have you been included in the decision-making-process and realisation of the therapy?"

Question j): "Do you feel that you have been sufficiently informed about the possible side effects of your therapy?

KU:

"It was all ok. I'm fine. It was all transparent and everything was fine". "I'm a spoke in the wheel but they all take care of me... . I'm a part of everything."

The interviewee KU replied positively to both questions i) and j). (e.g., "I am a spoke in the wheel ...I am part of everything".) This reply was not suitable for a word-by-word valuation. This means explicitly that the depressive, frustrated (= daunting) attitude (I am part of everything, I am a spoke in the wheel..) of the participant cannot be evaluated without the context. Also, the reply was not suitable for a word-by-word evaluation because of the individual choice of expressions which would not be repeated by other patients. The later use of comparability or valuation of nodes, interview questions and triangulation and to answer the research question: "how to assess the quality of oncological care" may not lead to a final answer. However, the researcher qualitatively assigned the following nodes to this answer: "assistance and support by the physician, information about diagnosis and treatment, continuity of support, quality of service, transparency and information".

SB answered the same question differently:

TABLE 22: INTERVIEW ANSWER (SB)

SB:

"Ugh ...break, yes,.... perhaps not pleased but certainly I totally agree. What you offered me and will help me, ...well, also, I did not really have any plans. Again, any personal information and help ... I'm feeling quite comfortable with you"

The patient answered with only a few words in a staccato manner. Sometimes the patient was expressionless, which was followed by an emotional sentence where the patient reflected upon his situation. These answers are not suitable for a standardised questionnaire. The assigned code words are: "appreciation for doctor and team, assistance and support by the physician, hope, acceptance".

Below are two examples of questions with low scores. In the first case, it was not clear if the patient needed support and whether he felt good or bad in his current situation.

TABLE 23: INTERVIEW ANSWER (SH)

Question i): "How much have you been included in the decision-making-process and realisation of the therapy?"

Question j): "Do you feel that you have been sufficiently informed about the possible side effects of your therapy?

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SH

"I must tolerate and accept the situation, I followed your suggestions. I feel discomfort from time to time and do not want to think about my future conditions. After radiation, I felt very bad, my condition changed. I need no cooperation. Everything depends on my resources; I have my family, sisters and my brother and they support me. I need no additional support or help".

The excerpt above demonstrates that patient SH was unable to adapt to the realities of his illness. He was assigned negative grades by the researcher for the following nodes: "consolation, cooperation, concerns, personal stress". An example demonstrating the five stages of grief identified by Kübler-Ross and Kessler (2005) is to be found in the answers of patient SG. The patient demonstrated the phases of denial and anger in the two questions.

TABLE 27: INTERVIEW ANSWER (SG)

### "How did you feel when given your diagnosis?"

SG:

"Firstly, I don't understand anything at all. I was told something ...I did not just ask them but if I wanted to speak to someone then I could speak, but I did not want to hear of it, nothing".

Patient SG did not recommend the medical practice because an institution in which people are sick and in which only severely ill patients are treated cannot be recommended.

TABLE 28: INTERVIEW ANSWER (SG)

SG:

"Nobody wants that! It is not a cold! I would say you can go there for treatment but it will be better if it is not necessary!"

The less-than-favourable-evaluation of this statement to recommend the medical practice can be seen positively in the context of her otherwise positive attitude. Even though this patient did not explicitly recommend the outpatient unit, her generally positive attitude was taken to mean that she saw the practice in a positive light.

The following answer gives an example for the stage of acceptance:

TABLE 24: INTERVIEW ANSWER (SG)

Question a): "How do you feel today? What do you expect of your treatment at this medical practice?"

Question b): "What outcome do you hope will result from the completion of your treatment at this medical practice?"

SG:

"Well, I feel fine. Yes, hope, hope that I be there, a bit more, hope I feel better every day. Yes, I have hope. I thought it would be worse".

These questions cannot be evaluated literally because of the complexity of patient feelings. Patients can feel positive, euphoric and enthusiastic despite being in poor physical condition. Kübler-Ross and Kessler (2005) propose that there are five stages of grief: denial, anger, bargaining, depression and acceptance.

The answers from patient PR give an example for denial and bargaining: TABLE 25: INTERVIEW ANSWER (PR)

Question c): "What are your main concerns and fears relating to your situation?"

Question j): "How much have you been included in the decision-making process and realisation of the therapy question?"

Question k): "To what extent do you require additional psychological support?"

Question n): "How burdensome and stressful are the traveling distance to chemotherapy and consultation hours?"

PR:

"I have just talked about this with my general practitioner and he said: You do this right now! This was a clear choice for starting a therapy made by my doctor, but the doctor explained all aspects to me and I could make a distinction.

I don't want suffering from pain and disease. I am a person having fun and joking, I'm not so serious. I have all information and understanding.

The travel distance is not exhausting. I try to avoid things that could happen which are unpleasant or hurt me. My wishes are taken into consideration. I get along very well".

These answers were assigned to the nodes: "appreciation doctor-staff, assistance and support by the physician, hope, integration and personal needs, trust in the doctor, appropriate treatment, information about treatment, patient activation, continuity of support, personal stress, transparency and information". Patient PR avoided answering some questions directly but expressed considerable uncertainty, sorrow and fears relating to his medical and personal situation.

### Critical comments:

For negatively posed questions, the higher sum-score is assigned to "bad".

For example, question "k": To what extent do you require additional psychological support? A confirmation of this question means at the same time, a lower total sum score. If the patients do not need psychological support and do not express

an opinion, they receive the valuation of "null". If possible the questions should be raised positively, because yes=positive, no= negative means it simplifies the ensuing interpretation and reduces bias.

### 5.1.3 Node evaluation

An individual grading system was used in the analysis phase to break down the results of the interviews (node evaluation, see section 4.4.2 Node evaluation). The grading system helped to identify the nodes which patients rated particularly positively or negatively (see Table 72).

### **Importance**

The nodes represent the many different elements of oncological QOC. The assessment of the interview questions led to node evaluation. The question responses were evaluated in terms of the individual nodes that they alluded to. A limitation of the node evaluation is the value of null, which was not considered. If answers to a question did not refer to a node, they could not be interpreted and resulted in null values.

# 5.1.3.1 Original table, cross-diagram and sort table

The <u>original table</u> provides a sum of all the nodes and shows how well each patient evaluated the individual nodes and sub-nodes (see section 4.3.3 Thematic coding in interviews). The <u>cross diagram</u> depicts the comparison of the individual 'good' and 'bad' node ratings in both groups, seeking to identify patterns in patient node ratings (see section 4.4.4). The <u>sort tables</u> are the total sum of nodes from the original table and the cross diagram sorted in descending order. This table helps to filter and sort the results from the original table and cross diagram (see section 4.4.5 Sort tables).

# Original table

a) The <u>total sums of the rows</u> represent each patient's evaluation of the 31 subnodes. The following questions arise when attempting to interpret the original table:

Does the total sum of the rows of nodes depend on:

- The quality of treatment outcomes and/or the quality of the medical practice?
- Some theme, or pattern in patient perceptions of QOL and PS?
- The patient's individual personality traits or characteristics?

Is a patient's total scoring an expression of the quality of oncological care or instead of a positive or negative personal attitude?

- b) The <u>total sums of the columns</u> represent how the ten patients in each group valued every single node. The following questions arise when considering these columns:
  - Are highly rated nodes more meaningful than lower rated nodes for the evaluation of oncological QOC? In other words, are nodes that are given particularly 'good' valuations by patients especially important?
  - Can lower-rated nodes from patients with lower personal total scores be rated as exceptionally negative or in everyday life during the medical routines not relevant?
  - Could patients be explicitly assigned to individual nodes?

## Cross-diagram

The cross-diagram looks at how groups of patients who gave particularly high or low scores to nodes evaluated other nodes. The researcher observed how often the group who gave 'good' ratings to a certain node also did so for other nodes and vice versa. When these patterns arose in the cross diagram – so, when different patients either especially positively or negatively rated the same selection of nodes - the nodes were 'linked'. The frequency with which individual nodes were linked was referred to as "the grade of intersections". The total sum of nodes from the cross diagram with linking for good and bad was sorted in descending order. The following questions arise from the cross-diagram:

- What does the number of node intersections mean about oncological QOC?
- Is a high frequency of intersections an expression of good oncological QOC and vice versa?
- Does the frequency of intersections for a particular node depend on the oncological QOC in the medical practice, or is this somewhat dependant on factors on the node or the individual patient characteristics?
- Is a high frequency of "good" intersections an expression of good oncological QOC or an expression of a positive or negative patient attitude?
- Is a high intersection rate (nodes in field A) synonymous with good validation of nodes and/or especially representative for the evaluation of the QOC?
- On the other hand, is a lower intersection rate (nodes in field C) expression of bad validation of a node and/or lesser representative for the evaluation of the QOC?

### Sort table

<u>The sort table</u> was created to help filter and sort the results from the original table and the cross diagram. The total sums of nodes from <u>the original table</u> were sorted

in descending order. The table is divided into three fields (A-C). Field A contains node sums with high validation and field C those with lower validation. It was shown that in fields A and C of both the ASC and non-ASC groups, the five patients with the best total scores and the five patients with the worst total scores rated with a ratio of 3:2. The importance of the significance of this observation is discussed in section 5.2.1.

### 5.1.4 Question-evaluation-tables

The following tables, TABLE 26-TABLE 29, highlight the interview questions from "a to o". The size of fields A and C were determined by the transfer of the descending sorted sums. For fields A and C of the original table, eight nodes were assigned. In the cross diagram, ten to eleven nodes were assigned. For each node, the valuation (+3/-3) of questions (a-o) was separately added so that the researcher could determine what questions had particularly high or low valuations. Following this, the nodes were sorted separately for field A and C, for the original table and the cross diagram rated "good". The node evaluation through validation of questions "a to o" requires that the interview questions could be answered. Consequently, a node evaluation could only be performed for good. The cross diagram for "bad" compared links to groups with low values. The mark "null" was assigned to questions that were not answered.

# 5.1.4.1 Results from the question-evaluation original table

TABLE 26 examines field A from the original table. Questions with high and low values are identified and compared towards the groups with and without ASC and towards the results from the cross diagram. More specifically, a comparison of the original table with the cross diagram and a comparison of both ASC and non-ASC groups was made. The interpretation of the data takes place in the following section.

TABLE 26: RESULTS FROM THE QUESTION-EVALUATION ORIGINAL TABLE (FIELD A)

Field A				
Questions with high valid	lated answers:			
Without ASC	c, f, g, h, i, j,	k, I, m, n, o	(comparison cross diagram:	f, g, h, l, m, n, o)
With ASC	f, g, h, i,	l, m, o	(comparison cross diagram	f, g, h, i, l, m, o)
Questions with low valid	ated answers:			
Without ASC	a, b		(comparison cross diagram	a, b, d, k, n)
With ASC	a, b, c, k, n		(comparison cross diagram	a, b, c, k)
Answers with concordan	t validations with and wit	thout ASC:		
Questions with high valid	dations concordant with a	and without	ASC:	
	f, g, h, i, l, m,	, 0	(comparison cross diagram	f, g, h, l, m, o)
Questions with low valid	ations concordant with a	nd without	ASC:	
	a, b		(comparison cross diagram	a, b, k)

# RESULTS FROM THE QUESTION-EVALUATION ORIGINAL TABLE (FIELD C)

Like TABLE 26, TABLE 27 displays the questions from field C in the original table that had answers that were particularly well or poorly evaluated. These are compared with the results of the cross diagram. Also, a comparison was made between results from the interview of the original table with the cross-diagram as well as a comparison between the ASC and non-ASC. The interpretation of the data takes place in the following section.

TABLE 27: RESULTS FROM THE QUESTION-EVALUATION ORIGINAL TABLE (FIELD C)

Field C			
Questions with high valid	lated answers:		
Without ASC	c, f, k, l, m	(comparison cross diagram:	c, d, f, g, h, i, j, l, m)
With ASC	h, l, m, n	(comparison cross diagram	b, c, h, l)
Questions with low valid	ated answers:		
Without ASC	a, d, e, g, h, i, j, n, o	(comparison cross diagram	a, k, n, o)
With ASC	a, d, e, f, g, j, k, o	(comparison cross diagram	a, d, e, f, j, k, m, n, o)
Answers with concordant	t validations with and without ASC:		
Questions with high valid	dations concordant with and without	ASC:	
	l, m	(comparison cross diagram	c, h, l)
Questions with low valid	ations concordant with and without	ASC:	
	a, d, e, g, j, o	(comparison cross diagram	a, k, n, o)

# 5.1.4.1.1 Comparison between the original table and correspondent question-evaluation-table

### 1. Observation field A + C

Field A included the ten nodes with the highest points.

Field C included the ten nodes with the lowest points.

The scores of the five patients with the highest total amount of points were better than those of the five patients with the lowest amount of points by a ratio of roughly 3:2. This can be observed both in the ASC and non-ASC group. It is, however, of note that field C in the ASC group had a strikingly low total number (Appendix method chapter C: Sort table original table).

In both groups, the three patients with the highest personal scores in field A gave particularly good assessments to the following nodes:

6 (integration and personal needs), 10 (acceptance), 12 (adequate treatment), 19 (patient activation), 21 (continuity of support), 24 (quality of service), 27 (transparency and information).

In both groups, the three patients with the collective lowest personal total scores in field C assessed the following nodes as being particularly bad:

1 (appreciation), 4 (consolation), 11 (accessibility), 13 (alternative treatment), 15 (enough time), 31 (far from practice social aspects).

In both groups, the following three nodes with the combined lowest total scores in field C were:

4 (consolation), 13 (alternative treatment), 31 (far from practice social aspects).

Concordantly, the questions "I and m" were given good evaluations in both fields A and C. ("I" for cooperation and information with other doctors; "m" for coordination and waiting-times). In contrast to this, the questions "g, j, o" in field A had the highest discrepancy: "g": the doctor listens attentively to problems and takes them seriously, "j": the patient feels that he/she has been sufficiently informed about the possible side effects of the therapy, "o": Would recommend the medical clinic to friends and relatives if they suffered from cancer. Node 26 (rush) and 29 (financial situation) were given null scores because they were not brought up by the patients in the interviews.

### 2.) Observation field A:

In both the ASC and non-ASC groups, nine of ten nodes recur consistently in field A (12, 21, 19, 27, 24, 6, 10, 7, 25). Node 12 (adequate treatment) is given the highest score in both groups. It is also the case that both groups consistently give high ratings to the questions "f, g, h, i, l, m, o". This includes "f" which refers to being able to speak with the doctor in a relaxed atmosphere, "g", which provides that the doctor listens attentively to problems and takes them seriously, "h", which refers to various treatment options, "i", which deals with the decision-making process and therapy, "I", which refers to the fact that treating doctors reach out to other medical institutions and colleagues, "m", which has to do with the coordination of appointments and "o", which asks whether patients would recommend the medical practice to friends and relatives if they suffered from cancer.

These questions can all be thematically sorted into three main nodes: interpersonal (f, g), medical (h, i) and organisational (l, m, o). They refer to structure-, process-, and outcome parameters. The questions "a and b" were given consistently "poor" ratings in both groups. "a" stands for good condition and what patients expect from their treatment and "b" stands for hope and outcome after completion of treatment at the medical practice. In field A, node 22 (coordination) only features in the non-ASC group and node 2 (assistance and support by the physician) can only be found in the ASC group. For node 22 (coordination) in the non-ASC group, the answers that provided particularly high scores were in response to the questions "I, m, and n". Question "I" stands for the doctor's cooperation with other medical institutions, "m" for coordination and waiting-times and "n" questions if it is burdensome for patients to come in consultation hours.

In the ASC group, node 22 was only referred to in answer to question "m": "coordination and waiting-time". This resulted in a low total amount of points for the node. The difference in scores for node 22 can be explained by the fact that it came up in several questions in the non-ASC group but only in one question in the ASC group. Node 2 (assistance and support by the physician) can only be found in field A of the ASC group. The questions with the lowest scores must be considered to clarify this. In both groups, the questions "a, b, c, k, n" were given low evaluations. This relates to the questions about the patient's condition and welfare, their hopes, sorrows and fears, stress due to travelling distances and the wish for psychological support. Node 2 can be found with a lower score in field B of the non-ASC group. This can be explained by a poor evaluation (as in node 2 with ASC) of questions "d" (sufficient information about disease and treatment options), "e" (explanation given about diagnosis), "h" (statement about various treatment options) and "j" (sufficiently informed about possible side effects of the therapy).

# 3.) Observation field C

Of the seven nodes with the lowest total amount of points, five nodes (4, 13, 14, 30, 31) appear in both ASC and non-ASC groups.

These five nodes were especially highly valued in particular questions: "c" for node 4 (What are your main concerns and fears relating to your situation?); "h" for node 13 (How well have you understood the various treatment options available to you and the severity of your illness?); "l" for node 14 (How well do you feel that the doctors treating your cancer disease reach out to other medical institutions on your behalf?); "k" for node 30 and "c" and "k" in node 31 (To what extent do you require additional psychological support?).

Nodes 5 (hope) and 28 (waiting-times and travel distance) only appear in field C in the ASC group. In the non-ASC group, they appear in field B. These nodes, however, are only selectively chosen, e.g. node 5 in question "b" (touches on the theme of hope), question "m" (the issues of cooperation) and, "n" (burdensome for patients to come to consultation hours). All nodes were selectively highly validated and referred to in one or a few thematically similar questions. These questions seem to be of importance for patients but are unsuitable for comparison within the original table. For instance, in node 13 (alternative treatment) the question "h" (How well have you understood the various treatment options available to you and the severity of your illness?) is given a high valuation in both groups. Node 13 was only referred to a few times in other questions. Equally important was node 14 (cooperation) which was uniquely well-rated in question "l": "How do you evaluate cooperation and information with other doctors?" The low num-

ber of points assigned to nodes 13 and 14 is partially limited due to careful questioning. A relatively small number of patients raised issues which were not related to the individual needs of the surgery but were assigned to nodes 29, 30, 31 (far from practice: financial, social, personal).

# 4.) Observation of the results from the original table and question-evaluation-tables

In <u>field A</u> of both groups, the questions "f, g, h, i, l, m, o" were concordantly highly validated. "f" refers to a patient's ability to speak with the doctor in a relaxed atmosphere and "g" to the idea that the doctor listens attentively. The question "h" has to do with patient understanding of various treatment options, "i" with decision-making process of the therapy, "l" with a doctor's cooperation with other medical institutions, "m" with scheduling appointments and waiting times, and finally "o" with whether a patient would recommend the medical practice to friends and relatives. In both groups, the questions "a and b" had lower scores in field A. "a" refers to the patient's general health condition and "b" to a patient's hope. The questions "f, g, h, i" refer to cooperation and communication with the treating doctors. The questions "I and m" which refer to information and cooperation of the treating doctor with other institutions are of great importance for the patients. Another highly valued question was "o" (would the patient recommend the medical practice).

In <u>field C</u> of both groups, the questions "I and m" were concordantly highly validated. "I" refers to doctor's cooperation and exchange with other medical institutions and "m" to scheduling appointments and waiting times. The questions "a, d, e, g, j, o" had lower scores in field C. "a" refers to general condition, "d" information about disease and treatment, "e" to explanation about diagnosis, "g" the doctor listens attentively, "j" shared-decision-making, and "o" to whether the patient would recommend the institution. The nodes in field C are not poorly voted because they represent poor quality or missing acceptance of disease and diagnosis, but rather because they only apply thematically to a selective amount of questions from "a to o".

In <u>fields A and C</u> of both ASC- and non-ASC groups, the questions "I and m" were highly validated. Thus, access to patient information and the cooperation of the treating doctor with other institutions (question "I and m") are of great importance for the patients. This notably supports the concept of ASC.

## 5.1.4.2 Results from the question-evaluation cross diagram

TABLE 28 examines field A from the cross diagram for "good" and identifies questions with high and low values. These questions are compared in the ASC and non-ASC groups. Exceptionally high and low evaluated answers are listed separately. The interpretation of the data takes place in the following sections.

TABLE 28: RESULTS FROM THE QUESTION-EVALUATION CROSS DIAGRAM (FIELD A)

Field A			
Questions with high validated answers:			
Without ASC	f, g, h, j, l, m, n, o	(especially high value for questions	f, g, h, l, m, o)
With ASC	f, g, h, i, l, m	(especially high value for questions	g, h, l, m)
Questions with low validated answers:			
Without ASC	a, b, d, k	(especially high value for questions	a, k)
With ASC	a, b, c, e, j, k, n	(especially high value for questions	a, b, c, e, k)
Answers with concordant validations with a	nd without ASC:		
Concordant with a high total score of nodes in field A:	f, g, h, I, m, o		
Concordant with a low total score of nodes in field A:	a, b, k		
Especially discordant are question "a, b, c, j"	with lower scores for ASC		

## RESULTS FROM THE QUESTION-EVALUATION CROSS DIAGRAM (FIELD C)

TABLE 29 presents field C of the cross diagram for "good". The questions with high and low values are identified and compared with and without ASC. Exceptionally high and low valuated answers are listed separately. The interpretation of the data takes place in the following sections.

TABLE 29: RESULTS FROM THE QUESTION EVALUATION CROSS DIAGRAM (FIELD C)

Questions with high validated answe	ers:		
Without ASC	c, d, f, g, h, i, l, m	(especially high value for questions	c, d, h, m)
With ASC	b , c, h, i, l	(especially high value for questions	c, h, i, l)
Questions with low validated answe	rs:		
Without ASC	a, j, k, n, o	(especially high value for questions	a, k, n, o)
With ASC	a, d, e, f, g, j, k, m, n, o	(especially high value for questions	a, k, o)
Answers with concordant validations	s with and without ASC:		
Concordant with a high total score of nodes in field C:	c, h, i, l		
Concordant with a low total score of nodes in field C:	a, j, k, n , o		
Especially discordant are question "a	" with lower scores for ASC		

# 5.1.4.2.1. Comparison between cross diagram and correspondent question-evaluation-table

The cross-diagram aims to examine to what extent the evaluation of a node stands alone or reflects the overall oncological QOC. The analysis and evaluation of the question-evaluation cross diagram without consideration of results from the total scores in the original table is not advisable. The researcher follows, therefore, triangulation as performed in the following chapter.

### 5.1.4.3 Comparison of positive and negative valuation

Patients of the upper third of "highly" valued nodes from field A of the original table belong in many cases to the upper third of the highly linked nodes from the cross diagram for "good". These patients seem to evaluate QOC <u>positively</u>. That affects patients: (SB, NJ without ASC), (FG, GR with ASC) with interview questions referring to question "g": trust in the doctor, questions "d", "h", "i": patient activation (the term stands for active involvement of patients in the process of medical treatment), and question "o": to recommend the organisation".

The following table provides examples of answers of these participants that show a positive evaluation of the QOC.

TABLE 30: INTERVIEW ANSWER (SB, NJ, FG, GR)

SB: "Ugh...difficult... I think, in so far I would like to know ..it is enough. Perhaps I don't want to know everything. I didn't really have any plans. From my expectations, I think the treating doctor is doing the best for me. Ugh.. that is my intention, well as said, I'm not interested in knowing all about my illness. I accept what you have suggested, and I assume that is the best for me. In any case, I'm very impressed with the help and support from the doctor, the team". NJ: "I would like to say: Yes. I will get healthy and trust in 100 % the doctor, the team, the practice". FG: "I have no problems with this. It was not too fast. All my wishes are considered. It was not too rapid. I wanted that. I was always the decision maker. Come back to you, well, all things are perfect, very good" GR: "I found out that you told me nothing good, ...it was too urgent, oh...oh I can expect, nothing good to me. All these alarm bells ringing for me. I definitively want to do something. I will not hesitate. I would definitely recommend you. All things are fantastic here and well organised, it is a pity that I'm so ill otherwise I would come more often".

In the following table, examples of patient answers can be found that demonstrate a negative evaluation of the QOC.

Patients of the lower third of "low" valued nodes from field C of the original table belong in many cases to the higher third of the highly linked nodes from field A out of the cross diagram for "bad". They seem to evaluate the QOC <u>negatively</u>. That affects patients: (EW, HD without ASC), (KI, GB with ASC).

Interview questions refer to question "g": trust in the doctor, questions "d", "h", "i": patient activation, and the question "o": to recommend the organisation".

TABLE 31: INTERVIEW ANSWER (EW, HD, KI, GB)

"What do you mean by sufficiently and adequately informed? Sufficient, yes, but sometimes I wish one or two sentence more .. well, how can I say this.... It depends that I can always think a step ahead, it depends on my individual experience, uhh....you could have mentioned a few sentence more...I feel okay..., well, but at the beginning, when the cancer came back, there was no need for talking, no... I know what it is about, but one would have expected more information, it would be ...." HD: "Actually, there was really only one option, only chemotherapy. That's the only option. Well, all in all I'm in a poor condition. Everything happens exactly as could be predicted. I have changed, I can simply cope much better with things now. I understand that, it is essential to maintain and improve quality of life. You do your best for this." KI: "...! didn't know this beforehand, but it becomes more apparent...well, I believe I'm a part a wheel of this all, I'm planned, scheduled. Trust is a thing that should be given to you, that's just the way it is." GB: "Right away someone declared what was important for me and what was the best for me and what I should do best. One option was chemotherapy and I ended up doing exactly that. Well, I understood everything, realized everything. Well, if you are so ill then you had to go in this institution."

Nodes with a high differentiation for "good and bad" as well as high significance for QOC referred to the contents of "trust in the doctor, patient activation, and to recommend the organisation". All these nodes are also evaluated with a high total sum-score.

Additionally, questions with a high value in nodes with a high intersection grade for "good" were found regarding the themes "adequate treatment and transparency and information". A high correlation for questions "to talk with" and "be listened to by the doctor", "information about adequate treatment", "shared-decision making" when it comes to the implementation of therapy, the importance of "sharing information with other colleagues", the "quality of service", "coordination" were related with a great willingness to recommend the medical practice.

5.1.4.4 Triangulation by comparison between cross diagram, original table and correspondent question-evaluation-table

The comparison between the cross- and original-tables should answer the question of whether the evaluation of nodes from the original-table depends on the combination of respective patient groups (patient dependent), node characteristics (node dependent), or on the individual evaluation of nodes to estimate the oncological quality of care in medical practice. Question-evaluation-tables are used to form comparisons. Moreover, three sort tables (the original table, the cross diagram for "good" and the cross diagram for "bad") were compared. This comparison resulted in nine combinations. The constant comparison method takes place with consideration of the question- evaluation-table. Notably, some nodes can always be found in all A and C fields (see Table 85: Question evaluation original table).

# 1.) Observation of constant concordant nodes in field A (in table 31 sort table major comparison):

Consistently concordant nodes in field A can be continuously found in all or nearly all combinations of the original-table and cross-diagram, in both ASC and non-ASC groups. This relates to nodes: 7 (trust in the doctor), 19 (patient activation), 25 (recommend the organisation).

For node 19 (patient activation) it should be observed that the node is concordant in the cross diagram for "good" but one point below the range of field A. However, this node tends to follow a similar pattern to those of node 7 (trust in the doctor) and 25 (recommend the organisation). The constant nodes can be viewed separately in field A of the "good" and for the "bad" cross diagram. The patients of the upper and lower thirds towards these nodes are compared below.

TABLE 32: PATIENTS FROM THE UPPER AND LOWER THIRD OF CONSTANT NODES IN FIELD A OF ORIGINAL AND CROSS DIAGRAM

#### Field A without ASC (table for "good" and table for "bad") node 7 (9/9) good: AK, HD, SG bad: EW1, KU1, SH, TA good: KU1, NJ, SB, TA node 19 (5/9 bad: AK, EW1, PR node 25 (8/9) good: AK, NJ, SB, PR bad: EW1; KU1; SH; TA Field A with ASC (table for "good" and table for "bad") node 7 (9/9) good: FG; GR; HW; TH bad: FHJ; GB; KI; KE node 19 (5/9 good: FG, GR; KE; TH bad: GB, HW, KI node 25 (8/9) good: EW2; FG; GR bad: GB; HW; KI; KE

Which patients can be found in the upper third of these constant nodes 7, 19, 25 in field A?:

#### Without ASC for good:

Patient: AK can be found in node: 7+25, NJ 19+25, SB19+25 (comment: node 7 is a limited category of three patients)

#### With ASC for good:

Patient: FG and FR are to be found together in all three nodes (comment: node 25 is a restricted category of three patients)

#### Without ASC for bad:

Patient: EW1 in all three nodes, KU1, SH, TA in nodes 7 + 25,

(comment: 25 and 7 are a restricted category of four, node 19 is a restricted cate-

gory of three patients).

#### With ASC for bad

Patient: GB and KI in all three nodes in the lower group with ASC, KI node 7 + 25, HW node 19 + 25.

Almost all patients in the upper third of these three nodes in field A of the "good" cross diagram had relatively high total scores in the original table. Similarly, the patients in the lower third of the "bad" cross-diagram with ASC had overall low scores in the original-table. There is a clear correlation between high scores in the original table and a high frequency of "good" intersections in the cross-diagram as well as between lower total scores in the original table and a high frequency of

"bad" intersections in the cross-diagram. Patients SB and NJ (without ASC) and patients FG and GR (with ASV) are the participants with the highest total scores. Their scores only appear in the "good" field A. This could be the result of positive personal attitudes or awareness of the positive quality of oncological care. Patients EW1, HD (without ASC) and KI and GB (with ASC) are the participants with the lowest total scores. Their scores are to be found in nodes with a high frequency of "bad" intersections. This could be either seen as an expression of negative personal attitude or as an adverse reaction to the quality of oncological care.

# 2.) Observation of constant concordant nodes in field C (in table 31 sort table major comparison):

In field C, nodes are defined with lower total scores in the original table and lower intersection grades in the cross diagram for "good" and "bad". The following nodes appear consistently in field C in both ASC groups: 4 (consolation), 14 (cooperation), 20 (appointments).

(Comment: Node 30: far from practice cannot be evaluated because in the upper ASC group there were seven patients with nearly identical values).

TABLE 33: PATIENTS FROM THE UPPER AND LOWER THIRD OF CONSTANT NODES IN FIELD C OF ORIGINAL-TABLE AND CROSS-DIAGRAM

```
Field C without ASC (table for "good" and table for "bad")
node 4 (4/9)
                  good: SG; SB; TA; PR
                                          bad: HD, KU1, NJ, SH
node 14 (6/9
                  good: AK, SB; SH
                                          bad: EW1, HD, SG, PR
node 20 (4/9)
                  good: KU; NJ; SB; SH
                                          bad: AK, EW1, SG, TA
  Field C with ASC (table for "good" and table for "bad")
node 4 (4/9)
                  good: EW2; FG; HW; TH
                                          bad: FHJ, GB, KE, KU2
node 14 (6/9
                  good: FHJ, HW; KU2
                                          bad: EW2, FG, KI, TH
node 20 (4/9)
                  good: EW2; FG; GR; TH
                                          bad: FHJ, GB, HW
```

Which patients can be found in the upper third of these constant nodes 4, 14, 20 in field C?

#### Without ASC for good:

Patient: SB can be found in node: 4 + 20, SH 14 + 20,

#### With ASC for good:

Patient: EW2 can be found in node 4 + 20, FG in 4 + 20, HW in 4 + 14

## Without ASC for bad:

Patient: EW1 and SG in node 14 + 20, HD in node 4 + 14

## With ASC for bad

Patient: FHJB and GB in node 4 + 20

The nodes 4, 14 and 20 recur in field C of the nine combinations of the original table and cross diagrams. However, they cannot achieve the high level of constancy that the nodes 7, 19, 25 obtain in field A. The patients in the upper and lower third of these nodes appear in diverse groups of patients. It can, therefore, be concluded that the nodes from field C do not follow a general trend.

Node 14 (cooperation) and node 20 (appointments) are valued selectively "good" in specific questions despite a low total score. For node 14, only responses to question "I" (cooperation and information with other institutions) apply. For node 20, the questions "f" (to speak with the doctor in a relaxed atmosphere), "m" (appointments and waiting- times), and "n" (travelling distance and consultation hours) apply. The low total score of nodes 14 and 20 can be attributed to the limited thematic reference on these nodes. This can result in a node-specific poor evaluation.

#### 3.) Observation of discrepant nodes (in table 31 sort table major comparison)

The original-table also displays less discrepant nodes (among the first 10 nodes), among which are nodes 2, 3 and 23 (assistance and support by the physician, concerns, personal stress). These nodes show non-comparable trends in comparison with the cross diagram. Thus, no relationship can be derived between original-table and cross- diagram for these nodes.

# The discrepancy between original-table and cross-diagram with the example of node 13 (alternative treatment)

Node 13 (alternative treatment) is always given a lower score in the original tables. However, the question "h" (explanation about various treatment options) is always positively evaluated. Its concordance characterises node 13 in both groups with a lower score in the original table (field C) and with a high intersection grade (field A) in the "good" and "bad" cross diagrams. This constitutes a significant inconsistency which can be explained with the identical thematic reference from node and question "h". This leads to a selective evaluation of, e.g. node 13 with a lower total sum and a lower hit rate but a high value in question "h". That may be an example and explanation for the highly linked intersection rate in the cross diagrams despite a low total score in the original table.

<u>Without ASC</u>, the patients in the upper third of the original table gave an especially high rating to node 13. The patients in the lower third gave a lesser individual personal score to their total point scores. This explains the equal number of "good" and "bad" intersections in this group. The lower group <u>with ASC</u> consisted only of three patients. Of these, two patients had the lowest personal total scores and were consistently among the lowest ratings for individual nodes. However, the high intersection grade for "bad" can be explained by the lower personal total score of these patients in the lower third. In the group with higher scores, five patients shared the same score. This may be a limitation, as it could have resulted in a higher "good" intersection grade.

The discrepancy of a node that has a lower total score in the original-table but a higher intersection grade in the cross-diagram may also result from the fact that the patients of the lower third have lesser total scores and thereby give especially negative ratings to many different nodes. A discrepancy is that changes (regarding the group size) in the favoured group size of four participants can influence the grade of intersections.

## 4.) Observation of the results from the cross-diagram and the question-evaluationtables

In field A from the cross diagram, both in ASC and non-ASC groups, the questions "f, g, h, l, m, o" were all given consistently high ratings. These questions relate principally to the opportunity for patient-doctor-communication, information about various treatment options and shared-decision-making in treatment options. Questions "l" and "m" refer to internal and external cooperation and coordination, waiting-times and appointments, "o" pertains to the patient's recommendation of the medical practice. In field A in both groups, the questions "a" and "k" (How do you feel today? What do you expect of your treatment at this medical practice? To what extent do you require additional psychological support?) are consistently rated with lower values.

In field C, both with and without ASC, the questions "c, h, i, l" (c: concerns and fears, h: various treatment options, i: included in the shared decision-making process, l: information and cooperation with other medical institutions) were consistently positively rated. In field C, both groups gave consistently low ratings of questions "a, e, k, n, o" referring to "a" expectation of treatment at this medical practice, "e" explanation of diagnosis, "k" requirement of additional psychological support, "n" stressful travelling distance and consultation hours, and "o" recommendation of the medical practice.

#### Results:

Factors such as patient-doctor-communication, the process of shared-decision-making for treatment options and cooperation with other institutions were equally and positively evaluated both in fields A and C. In this context, the question-evaluation and original-tables are in agreement. The questions "a" (How do you feel today?) and "k" (To what extent do you require additional psychological support?) are consistently poorly valued in field A and field C. Furthermore, question "a" is always negatively valued in all fields and among involved participants, as well as the question-evaluation-original-table and cross diagram for "good". One reason for this could be that all patients had reached an advanced stage of cancer.

The results of this study are preliminary. Further research should examine the needs and perceptions of cancer patients more thoroughly. Throughout their disease, many patients activate a self-protection coping strategy with a defensive mechanism. These patients respond to their reality with denial, fight, fear, anger, or depression. As Kübler-Ross and Kessler (2005) mentioned, the fact of grieving about being terminally ill can make patients 'crazy'. They want to say that they feel fine because, as Kübler-Ross and Kessler (2005) point out, we live in a culture that does not know how to understand the process of grief and encourages one to live life as normally as possible. It is necessary to understand patients' perceptions and their expectations if they want to keep on moving in their life, go to work, stay at home; it does not work that way due to the status of their severe illness. For most patients in general, it was important to find hope and have their beloved family surrounding them and have support. The process of adaption is linked with a patient's grief processes. For example, patient SG (a patient who had a bad QOL) replied to the question: "What are your main concerns and fears relating to your situation?" in the following manner: "It was not worse than anything I had imagined. My husband takes care of everything. He cooks, I sit at the table and grab some food. He was pleased about that. Yes, that makes him happy, considering that I am still here".

#### 5.1.5 Questionnaire synthesis and comparison with the interview

#### Results without ASC

Eight of ten patients without ASC had concordant statements. Two statements (those of one female and one male participant) were discrepant. This can be explained in the first case by the poor general state of health of the female patient VI SG. Paradoxically, this patient had a high degree of satisfaction despite her deteriorating health condition. In the second case, by the attitude of the male patient II EW, who was not talkative in the interview.

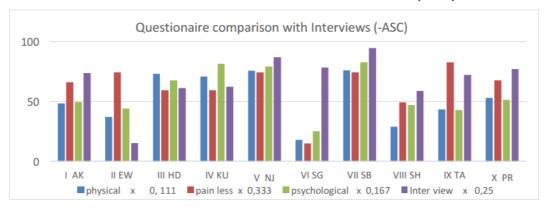
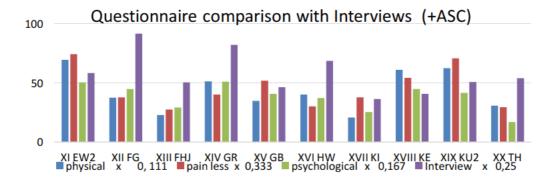


FIGURE 10: QUESTIONNAIRE COMPARISON WITH INTERVIEWS (-ASC)

#### Results with ASC

Four patients, one female and three male (FG, GR, HW, TH) had discrepantly higher values in the interview than in the questionnaire. Only six patients made concordant statements in the questionnaire (EW2, FHJ, GB, KI, KE, KU2). Patients FHJ, GB, and KI were concordantly low in the interview and questionnaire as well.

FIGURE 11: QUESTIONNAIRE COMPARISON WITH INTERVIEWS (+ASC)



It is important to note that both the questionnaire and interview results in the group without ASC had higher scores than those in the group with ASC. In the questionnaire, the themes of physical, psychological and pain in the Non-ASC group are evaluated significantly better than in the group with ASC. It can thus be determined that PS (based on the interviews) and QOL (based on the questionnaires) are rated congruently and follow similar patterns. This affects the behaviour of the entire group. Only in individual cases can divergent behaviour be observed where, for example, a patient answered a question positively in the interview and negatively in the questionnaire or vice versa.

#### Results:

If a patient achieves a much better outcome in the interview than in the questionnaire, it could hint at either a high level of acceptance of the disease and situation or could express a great sense of trust in the doctor and particular appreciation for the quality of oncological care. The combined application of interview and questionnaire helps to demonstrate whether QOL and PS behave in the same way or contrarily. This comparison can be used to assess the quality of oncological care better. Thus, considering QOL and PS in this research seems to be suitable for the evaluation of the quality of oncological care in the medical unit.

#### 5.2 Results

In this case study, the researcher ensured that systematic procedures were put in place to aid later comparisons, which will be based on the gathered data. The data analysis and synthesis sections focussed on making comparisons to answer the research questions. In the methods chapter, the specific features of each case and the group of participants were described in depth.

#### 5.2.1 Summarisation of the analysis and synthesis of the interviews

It has been investigated to what extent it is sensible to reproduce all aspects of oncological QOC in 31 nodes. The nodes and all related questions and answers were compared and contrasted in different ways. The following summary will outline the observations that resulted from the analysis and synthesis of the generated data. In the original table, the nodes were sorted in descending order of their total scores. The nodes were allocated a high, middle or low score in fields A, B and C. Special focus was placed on the nodes with high scores in field A and nodes with low scores in field C. The question arose as to whether the nodes in fields A and C represent thematic trends for a better or worse evaluation of QOC in the medical practice (the situation can change from one medical unit to another).

In the sorted original table, it was shown that in fields A and C of both ASC groups, the five patients with the best total scores and the five patients with the worst total scores could be compared on a ratio of 3:2. The fields A and C do not reflect the classification of individual patients, but rather that of nodes which were consistently either positively or negatively evaluated. Fields A and C of the original table in the ASC and non-ASC groups matched. This suggests that the concept of having 15 interview questions to which 31 nodes are allocated is not focused on the individual patient, but rather on the entire oncological quality of care of the respective practice. There was no typical patient from field A or field C (good or poor). This means that patients with high total scores did not score particularly well in one field, and patients with lower scores did not score especially poorly in one field. The patients with the highest personal scores in the original table gave

the best scores to node 12 (adequate treatment), 19 (patient activation), and 27 (transparency and information). All three nodes are related to medical characteristics like trust, medical competencies and integrated patient care. Thus, a positive validation of these nodes could be of great importance for a positive overall assessment of the medical unit.

In field C of the original table, both with and without ASC, the following three nodes had the lowest total scores: 4 (consolation), 13 (alternative treatment), 31 (far from practice social aspects). One possible explanation for the observation of node 4 could be that the opportunity to give the patients consolation and encouragement was limited because medical staff had to provide patients with truthful information about the incurable nature of their severe diseases. This differs from situations in which staff treated patients with diseases that were not life-threatening. The lower total scores of nodes 13 and 31 are explained by a selective evaluation of a few similar questions. One could assume that the patients undergoing extreme care would suffer from psychosocial stress. However, the negative rating of these nodes did not correspond to the psychological part of the standardised questionnaires. For further considerations, these nodes will not be applicable; however, the related questions for "good" shall be answered.

In fields A and C of the original table, questions regarding cooperation, professional exchange, and organisational coordination of appointments were given high scores. This occurred both in the ASC and non-ASC groups. This is remarkable because these questions apply mainly to the priorities of the ASC model. Additionally, considering the nodes, all the interview questions were separately observed in field A and C of the ASC and non-ASC groups. This resulted in interesting similarities and differences. For instance: the fact that questions "a and b" (How do you feel today? What outcome(s) do you hope will result from the completion of your treatment at this medical practice?) were rated poorly in all fields of the original table is an indication of both the physically and psychologically poor condition of these very ill patients, who had very little hope of improvement due to the incurable nature of their cancer.

The questions "g"(Do you feel that your doctor listens attentively to your problems and takes them seriously?) "j" (Do you feel that you have been sufficiently informed about the possible side effects of your therapy?), and "o" (Would you recommend our medical practice to friends and relatives if they suffered from cancer?) obtained far better scores in field A than in field C. These questions are related to the patient-doctor-relationship and the willingness of patients to recommend the organisation. These questions could be used as indicators of patient appreciation of the oncological quality of care.

In field A without ASC, more positive ratings were found for the questions "c" (What are your main concerns and fears relating to your situation?), "j" (Do you feel that you have been sufficiently informed about the possible side effects of your therapy?), "k" (To what extent do you require additional psychological support?) and "n" (How burdensome and stressful is the travelling distance to therapy?). This could indicate that the patients in the non-ASC group were in better physical and psychological condition.

In both groups, field A of the original table displays the concordant highly-voted questions (f, g, h, i, l, m, o). These relate to the opportunity to talk with and be listened to by the doctor, information about alternative treatment, shared decision making when it comes to the implementation of therapy, the importance of sharing information with other colleagues, the quality of service, coordination, appointments and waiting-times and the willingness to recommend the organisation. In field A, these questions are thematically distributed amongst all three main nodes: interpersonal, medical and organisational. It appears that these questions are especially significant and representative for the evaluation of the oncological QOC.

In the <u>ASC group</u>, the lower score of node 22 (coordination) indicates a selective and exclusive reply to the question "m" (How did you find the scheduling, especially the ease of making appointments when you needed them and the waiting-time at external medical institutions? (coordination of appointments). This question is in itself being highly rated. This is an example of the fact that the total score of a node is not the only scale for the evaluation of quality.

The lower score of node 2 (acceptance and support by the physician) in the non-ASC group arose from the poor evaluation of questions which were related to patient information about his/her disease and treatment options. However, patient information about his/her disease and treatment options could cause more and explicit information about treatment and alternative treatment given within the compulsory introduction to the guidelines for participation in the ASC. Lower scores also arose if only a few patients expressed views about a particular node or if patients answered the questions in a fashion that did not apply to the nodes. The willingness of patients to make statements about particular nodes tended to depend on how well the individual had come to terms with the facts and consequences of the disease. It is still to be determined whether the evaluation of nodes depends only on a patient's acceptance of treatment or whether a patient's willingness and ability to express praise and appreciation also play a role. After all, the

individual evaluation depends not only on the content and topic of the questions but also on the individual attitude towards life and self-awareness of the patients.

In fields A and C of the original table, both in the ASC and non-ASC-groups, questions "I" and "m" were concordantly highly valued. "I" stands for the importance of the cooperation of the doctor with his colleagues and "m" for the quality of service of coordination of appointments and waiting-times. The high valuation of question "I" is limited to node 14 (cooperation). Node 13 (alternative treatment) is well-rated in question "h", which pertains to different treatment options. These questions that are higher rated in field A and C suggest that cooperation with other institutions and doctors, and coordination of appointments have great importance for the patients. This supports the concept of ASC. Only a few patients discussed topics which did not have to do with the medical practice and were therefore assigned to the nodes 29, 30, 31 (far from practice: financial, social, personal). The nodes 30 and 31 were generally given low values. However, they were better evaluated in response to question "k" about psychological support. Remarkably, no patient discussed negative personal matters that were "far from practice". The few comments associated with these nodes were always positively valued (+3 node evaluation table). Furthermore, nobody commented on financial matters.

In field C of the original table, both with and without ASC, the nodes relating to the questions "a, d, e, g, j, o" all received consistently low ratings. Forgetting for one moment the general condition of the patients ("a") (because all patients suffer from a poor general condition), the low ratings of nodes relate to the doctor-patient-relationship ("d, e, g, j") and are linked to a patient's willingness to recommend the medical practice ("o"). The quality of oncological care cannot uniquely explain the lower node scores in field C. The researcher cannot differentiate between poor evaluation scores and the lack of a thematic order caused by selective questioning. In nodes with lower total scores, the selectively high-valued questions require special attention, as they could provide information about oncological QOC. An obvious step to investigate this is to remove the selectively valued nodes from the original table for further investigation and to value the corresponding questions without considering the nodes.

In field A, all tables presented nodes 7, 19 and 25. This indicates a thematic group, which closely links trust in the treating doctor with patient integration and willingness to recommend the medical unit. These nodes have particular significance concerning the oncological QOC. In the case of the nodes with lower scores in the original table and simultaneously lower numbers of intersections in field C of the cross diagrams, it is hard to form a reliable connection with oncological QOC. Nev-

ertheless, it may well be the case that these nodes are thematically linked to others in specific questions and, therefore, actually could act as indicators of some aspects of QOC. The lower intersection grade of field C can be explained by the diversity of patients and does not necessarily influence the oncological QOC.

Doctor-patient-conversation, shared-decision-making and cooperation are equally highly valued in both fields A and C. Yet these three highly valued nodes offer consistency in the question-evaluation- table of the original table. The questions "a" (How do you feel today? What do you expect of your treatment at this medical practice?) and "k" (To what extent do you require additional psychological support?) were always given "low" ratings in fields A and C of the cross diagram. Question "a" was given a bad rating in all fields, in all tables and by all patients. The reason for this was that all patients suffered from an advanced stage of cancer. In the original tables of both ASC and non-ASC groups, question "k" in field A was poorly rated. The better evaluation of question "k" in field C was limited to the consistent nodes 30 and 31 which referred to personal and social conflicts. The lower intersections in field C also indicate lower relevance for the oncological QOC.

## Summary and evaluation of nodes

The data as mentioned above (section 5.1.3.1 Original table, cross-diagram and sort table up to 5.1.4.4 Triangulation by comparison between cross diagram, original table and correspondent question-evaluation-table) lead to the following conclusions:

1. A node that is highly voted in field A of the original table and has a high frequency of "good" intersections in field A of the cross diagram will be highly evaluated alongside most other nodes and therefore indicates a positive overall assessment of the oncological QOC. One limitation must be taken into account: patients from the upper group can randomly give "good" classifications to other nodes. This becomes increasingly likely if the upper group of patients always has the highest personal score.

This statement affects node 12 (adequate treatment), 19 (patient activation), 25 (to recommend the organisation) and 27 (transparency and information).

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#### TABLE 34: EXAMPLE OF PATIENT SB WHO ALLUDES TO MANY DIFFERENT NODES

SB:

"The whole organization and the personal support go hand in hand. It was so well organised, with clear and straight forward information and also therapy. I had no idea, I took note of what you say, I didn't need to worry about anything. Well, I am really impressed by the doctor and team I'm not in a position to answer. I'm not asking questions I do not want to hear things that I do not want to hear".

 A node which was highly validated in field A of the original table and has a low score for "good" in field C of the cross diagram is selectively positively validated but does not significantly impact the total score of oncological quality of care.

No node met these criteria.

3. A node which has a low score in field C of the original table and is highly linked in field A of the cross diagram for "bad" can often be linked with other poorly-rated nodes. This, therefore, indicates an overall negative assessment of the oncological QOC.

This statement affects node 15 (enough time).

TABLE 35: INTERVIEW ANSWER (PR)

Question f): "How easy is it to speak with your doctor in a relaxed atmosphere?"

PR:

"At the moment that goes so far. I'm satisfied, yes, yes.... Everyone comes to me and asks, ...ask how do you feel today. It is a standardized iterative sentence – meaningless."

4. A node which has a low score in field C of the original table and is poorly linked in field C of the cross diagram for "bad" will be selectively negatively validated but does not indicate important information about the oncological QOC. This affects nodes 4 (consolation), 14 (cooperation).

TABLE 36: EXAMPLE FOR CONSOLATION AND COOPERATION (KI & SH)

#### Example of patient KI for consolation:

KI:

"I really assumed that there is something, I thought as much. I am always getting worse. As the doctor said: you are seriously ill, you need palliative care, I thought about a source who can give me hope and consolation."

#### Example of patient SH for cooperation:

SH:

"Well, it was ok that doctors communicated and cooperated. It made a difference for me not to be at the mercy of one person."

5. If a node is often simultaneously linked to "good and bad", it seems to be able to differentiate particularly well between good and poor evaluations. For this reason, it has a great impact on and appears to be an indicator in the evaluation of the oncological QOC. If these nodes have high valued sum-scores, they are particularly significant for evaluating QOC.

This affects nodes 7 (trust in the doctor), 19 (patient activation), and node 25 (recommend the organisation).

#### TABLE 37: INTERVIEW ANSWER (FG)

FG:

"Well, it was all clear. The conversation with the doctor was informative, he had enough time and explained my diagnosis and treatment to me in a detailed manner. Medical support is excellent."

6. The linking grade of a node was influenced when it was thematically restricted and therefore only came up in a few questions. These nodes were poorly scored in field C of the original table in both ASC and non-ASC groups.

This affects nodes 13 (alternative treatment), 14 (cooperation), 30 (far from practice personal conflicts) and 31 (far from practice social aspects).

#### TABLE 38: INTERVIEW ANSWER (EW)

EW:

"must completely support my wife, she suffers from MS. Well, from an organizational perspective I must consider other appointments. Only chemotherapy was required, I don't care about myself and my disease. My wife really disagrees with me."

7. A high linking grade (nodes of field A: 7 (trust in the doctor), 11 accessibility), 13 (alternative treatment), 22 (coordination), 25 (recommend the organisation), 27 (transparency and information) of the cross diagram indicates a trend for good or worse evaluation of the medical unit.

A poor linking grade (nodes of field C: 2 (assistance and support by the physician), 3 (concerns), 4 (consolation), 5 (hope), 17 (information about diagnosis) indicates individual validation of a special node without greater impact for the oncological QOC.

TABLE 39: EXAMPLE OF PATIENT FOR "GOOD" AND "POOR"

# NJ: "The practice was great and well-organized. I do not care about anything. I receive my appointments; you know I must wait more than 4 weeks for appointments. I am extremely satisfied with you all, doctor and team." Example of patient for "poor" KE: "Ok, I am not so fine, incredibly dreadful. I know, I have such expectations,... on that day, well it was a mental damper. All in all, it could be worse..."

Patients seem to evaluate the QOC <u>positively</u> if they have a high total score and belong to the upper third in the original table with high linking scores for "good". For example, that affects patients: (SB, NJ without ASC), (FG, GR with ASC).

TABLE 40: INTERVIEW ANSWER (GR)

GR: "Well the doctor told me that an operation is not feasible, only chemotherapy, which won't cure the disease but I intend to do that. I do not hesitate, I had a good life, a good wife and children. I will handle that but I trust in the doctor and the team knowing they all do everything for me."

Patients seem to evaluate the QOC <u>negatively</u> if they have a lower total score and belong to the lower third in the original table with high linking scores for "bad".

For example, that affects patients: (EW, HD without ASC), (KI, GB with ASC).

TABLE 41: INTERVIEW ANSWER (HD)

HD: "At the moment, I need no psychological support. I do not feel very well, I'm in a bad condition. I always took care of myself, I've been healthy my entire life and was active. However, it is stupid waiting for a taxi driver, waiting for appointments, I cannot wait. I always made my things."

Summary and evaluation of the interview results:

Representative of good oncological QOC of one single outpatient unit seems to be the highly valued nodes 12 (adequate treatment), 19 (patient activation), and 27 (transparency and information), as well as the highly valued questions "f, g, h, i, j, l, m, o". These relate to the opportunity "to talk with" and "be listened to by the doctor", "information about adequate treatment", "shared-decision making" when it comes to the implementation of therapy, the importance of "sharing information with other colleagues", the "quality of service", "coordination", "appointments and waiting-times" and the willingness "to recommend the organisation". The nodes 7 (trust in the doctor), 19 (patient activation), 25 (recommend the organisation) were highly linked and evaluated and seemed to be mainly indicative of the evaluation of QOC.

Some nodes received only a few points in total. However, the thematically similar question of each of these nodes was good valued. That means the central theme of these nodes was only good valued by the thematically related questions. These nodes showed poor linking to other questions. This applies to the node "13 alternative treatment" and the corresponding question "h" understanding of treatment options; "14 cooperation" and the corresponding question "l" doctors treating patient's cancer disease with other medical institutions in cooperation; and nodes "30 and 31 far from practice personal and social conflicts" and the corresponding question "k" requirements of psychological support. Therefore, these nodes which are only selectively valued are not representative of the entire QOC. The nodes "13, 14, 30 and 31" should not apply in further studies.

On the other hand, their corresponding questions "h, l, k" were highly valued and should be further considered for the evaluation of the QOC. As these questions are thematically very important, they should be used in further applications. The question "l" regarding cooperation and the professional exchange was especially highly valued in the ASC group. One of the main topics of the ASC is cooperation with others and professional exchange.

#### 5.2.2 Questionnaire synthesis and comparison with interviews

Comparing the PS interview with the QOL questionnaire showed that high QOL and vice versa mainly accompanied high PS. An interesting tendency, especially in the group with ASC, was that four out of five patients with lower QOL in the questionnaire had a discrepantly better interview score. This means that a poor QOL is associated with an awareness of good QOC despite bad conditions, with a strong need on behalf of the patients for good oncological quality of care.

The individual semi-structured interview and the standardised analogous questionnaire complete each other regarding the evaluation for the oncological QOC.

The feedback from the questionnaires discovered no trends about the related influence of the main categories for physical, psychological and painlessness impact. How good patient treatment is affected by the patient's physical and psychological condition and vice versa cannot be specified in-depth. It remains unclear to what extent the treating environment influences the physical and psychological condition of patients. Furthermore, it is unclear to what extent the physical and psychological condition influences a patient's awareness of QOC.

## 5.2.3 Summary of data analysis and synthesis

Foss and Ellefsen (2002) point out that conclusions from qualitative and quantitative data might differ. That said, the knowledge gained from two approaches is not unreliable, but rather represents two separate perceptions of different realities. This is a critical aspect to bear in mind. The researcher of this study perceived only minor differences between the patients receiving care under the ASC model and those being cared for under the old model (see the section, 5.1.1 Comparability of the two groups with and without ASC). Because both groups of patients were similar, they constituted the perfect subject for a comparative case study.

Individual, one-to-one interviews were chosen for this case study. This medium allowed for spontaneous, unfiltered replies from the patients, which is of especial importance when one considers that the patients in question were all fighting life-threatening, mostly incurable diseases. The spontaneity of an open interview can often lead to incomplete and short dialogue and difficulty to speak or find words on the part of the patient. This considerably limits a researcher's ability to glean meaning from individual words and perform sentence analyses. It was therefore decided to allocate the interview answers to 31 thematic codes. The researcher subjectively performed the allocation. The evaluation developed its scale system that ranged from minus three for poor, to negative or disagreed, to plus three for good or agree.

The selected procedure in this qualitative research, which used nodes to depict the important aspects of oncological quality of treatment, proved to be practical and useful. The answers to the questions in the semi-structured interview paired with the grading systems of nodes helped the researcher to reach the study goals. Nodes with similarly high scores and a high frequency of "good" intersections seem to be representative of the high oncological quality of treatment. The nodes 7, 10, 19, 22, 25, 27 comprise: Trust in the doctor, the involvement and activation in treatment decisions, patient activation for shared-decision-making, information about possible side effects and ongoing procedures, acceptance of diagnosis, transparency and information about the examination and organisational procedures, quality of structural and organisational service, and patient willingness to

recommend the organisation. This applies to nodes that feature in all or nearly all combinations of the original-table and cross-diagram. These include node 7 "trust in the doctor", 19 "patient activation", and node 25 "to recommend the organisation".

Nodes with lesser scores and a lower frequency of intersections seem not to be representative of the oncological quality of treatment. However, they could reflect single shortcomings of the individual medical organisation. Answering selective questions must be evaluated separately, and the corresponding thematic codes must be considered and for further research excluded. Furthermore, the nodes far from practice should be deleted as well, because they may not be relevant for the evaluation of the oncological quality of treatment. A limiting factor, as many previous research studies have shown, is that when asked questions concerning the doctor or team, patients tend on average to answer more positively than negatively.

Further uncertainty arises from the fact that if patients refused to answer a question, that question was assigned the grade null. This refusal to answer questions could have represented a lack of consent for both negative and positive aspects. The failure to answer questions could also have signified that these aspects were irrelevant from a patient's perspective.

The constant comparison of PS in an interview and the QOL in a questionnaire is a sensible way of assessing the oncological quality of treatment. The results of this single qualitative study involve only a small number of patients (20) and are therefore not generalisable. This research could be expanded upon by narrowing down on particularly significant questions and nodes. This would allow for a simplification of this complex analysis procedure. Oncological practices must be able to assess their oncological quality of treatment, even when the conditions of the health care system change. There is a need for sensible and practical tools for evaluation of the quality of oncological treatment for a small number of patients in a medical unit.

The patients receiving care under the ASC system had an overall lower total score than the group without ASC even though they generally gave better ratings to questions about information on diagnosis and treatment options, side effects of therapy and alternative treatment. This could be explained by the fact that a more comprehensive information network exists under the ASC system to ensure patient understanding.

In both groups, questions about information and cooperation of the treating doctor with other institutions as well as the coordination of waiting-times and appointments were highly valued. These aspects are some of the direct objectives of ASC. Particularly in the ASC group, patients can be found with a lower QOL in the questionnaire but show in comparison a discrepantly better evaluation in the interview section. This finding could suggest a higher acceptance and approval in this group. At the same time, no significant differences between the oncological QOC in the two groups could be identified. In practical terms, shortly after the implementation of the ASC in the single outpatient unit, only a few changes in the oncological QOC can be detected. It seems to be difficult for the new ASC model to improve the oncological QOC in a medical practice which already meets the targets of the oncology guidelines.

#### 6.1 Introduction

The researcher's motivation to conduct this study was for medical institutions to receive information about the current state of quality of care and provide suggestions from patient feedback on ambulatory outpatient care. Based on quality management parameters from structure-process-outcome, the researcher points to the reference research of Kleeberg et al. (2005) as a foundation. The results of Kleeberg et al.'s (2005) PASQOC study suggest that QOL and PS are favourably influenced when a good medical outcome is achieved (Cella & Stone, 2015; Koller & Lorenz, 2003). PS and QOL have been comprehensively examined in extensive multicentre quantitative studies as mentioned before. These extensive quantitative studies have not been produced in a single outpatient unit with a small sample of patients. The illnesses and requirements of oncological patients are very heterogeneous, and therefore, it is not feasible to come to any significant conclusions about these different tumour disease characteristics. The discussion begins with a statement of the major findings of the study to answer the research questions.

This study aimed to determine to what degree a qualitative evaluation of PS and QOL can lead to conclusions regarding QOC. It also sought to determine how patients in a single outpatient unit interpret the quality of care that they are receiving under the existing healthcare model in Germany. Based on this information, the study aimed to determine what - if any - differences or improvements in QOC can be identified when comparing the interview and questionnaire results of patients treated under the ASC model with those of patients treated under the previous model. The results of the study demonstrate that it is feasible to use a qualitative evaluation of PS and QOL to estimate the QOC among cancer patients in an outpatient unit. This study revealed relevant key factors for QOC. Consent and high valuation demonstrate aspects of the doctor-patient-relationship, information on diagnosis and treatment options, quality of service and cooperation. The items with the highest relevance to estimating the QOC relate to "trust in the doctor", "patient activation" and to "recommend the organisation". These outcomes are very similar to the results of the quantitative PASQOC reference study. The mandatory requirements and the in-depth information and the interdisciplinary treatment may be an advantage for the new ASC model.

One issue for a specific doctor is to estimate how good the quality of the treatment is, and how beneficial for the patients. The changing situation in the health care

sector, confronted with a new regulation from government and the need for a rapid and easy to handle instrument to estimate the quality of care, was the starting point for the implementation of this research. Also, greater importance for quality management systems, for patients and providers is the current situation for the implementation of the ASC. For that, the researcher performed a comparison of the existing health care model in oncology with the new ASC.

In sum, the present research has contributed the knowledge that is highly relevant from an academic as well as from an economic point of view for the treating medical unit. The study contributed new knowledge to the discussion in the field of PS and QOL as well as to the methodological discussions in the broader field of social and human sciences. By developing a framework for the application of research methodologies in the context of a case study, the study provides a model for further research in this field. Most importantly, however, the resulting conceptual model and the development of a tool to evaluate the QOC of a single outpatient unit will support the individual medical practices as well as patients being treated under the oncology contract and those being treated under the new healthcare model.

The research points out the core contributions of the findings as an abbreviated version of the key understandings beginning with an interpretive summary. The next section addresses primary and secondary theoretical contributions related to the status quo, applicability and other related literature. After the research findings follow the practical implications with the discussion of the suggestions that will improve the current research. The section with limitations and opportunities arises from the data generation and the chosen research context. The researcher specifies how future research could explore or increase upon alternative and current research.

#### 6.1.1 Primary and secondary theoretical contributions

One of the key aims of this project was to estimate the oncological quality of care in one single oncological outpatient unit. Important elements for well-being of tumour patients undergoing oncological therapy are the legitimate hope of effective and tolerable therapy and the expectation of a good response. Beginning with the status quo and what other researchers have done so far, the following theoretical implications focused on insights directly related to the literature chapter and refer to earlier quantitative research. Previous studies focused on QOC and followed a quantitative methodological approach. In doing so, they pursued hard endpoints of remission rate and survival time but also aspects of structure- and process quality as well as softer indicators for outcome quality like PS and QOL. This allows a

comparison of differences of the medical unit with a large number of similar medical practices within the meaning of a benchmark. Notice, that no tool has been developed yet that allows prompt evaluation in a single outpatient unit with their own QOC based on selected patients. The chosen research design excluded a quantitative, mixed-method approach because quantitative indicators with a small and heterogeneous patient group in single outpatient practices would not be representative and statistically analysable. One of the key factors takes on special importance: if the oncological medical practice is confronted with changing regulations and cost control conditions in the health care system, then it will be important to gain a rapid, easy instrument to evaluate the quality of oncological care. Such a situation emerged with the implementation of the new health care model ASC. That repeated and strengthened the research question to qualitatively determine that PS and QOL can be used to evaluate patient QOC in a single outpatient unit. Furthermore, the question emerged of examining how patients in a single oncological outpatient unit in Germany interpret the quality of care in the previous healthcare model as compared to the care provided by the new ASC model.

#### Primary theoretical contributions

The outcome model depicted in Klinkhammer-Schalke et al. (2008) and Koller et al. (2009) points out that QOC is based on a complex intervention of oncological diagnosis, therapy and quality of life. The key message from the mentioned PASQOC study is the assumption of mutual interference from oncological tumour response and the resulting physical condition, satisfaction and quality of life. The quantitative research from Kleeberg et al. (2005) was performed on a large patient group (3384) and a large number of participating teams (24). The PASQOC study compared the results from a self-constructed questionnaire with the results of a standardised SF-36 questionnaire to answer the key questions for the recommendation of the oncological medical practice. Significant areas for improvement are the aspects of shared-decision-making, doctor-patient communication and organisation of care. The willingness to recommend the practice was based mostly on the doctor-patient relationship, premises, information about diagnosis and treatment options. This study emphasises the advantage in a qualitative approach of combining a semi-structured interview survey and an SF-12 applied analogous and generic questionnaire.

# <u>Secondary implications for theoretical insights (that apply to other related literature).</u>

The study from Klindtworth et al. (2010) also challenges the advantage of a qualitative narrative interview in oncology in a palliative care setting (10 patients + 9 family members). One reason for this study was the aim of using qualitative inter-

views for improving a practice-oriented quality management system to receive information from patients and family members that can be rapidly implemented. The possibilities to improve the information from an HRQOL quantitative questionnaire (EORTC QLQ-C 36) as a disease-specific questionnaire in cancer therapy with a combined identical patient interview (95 cancer patients) was explored by Groenvold et al. (1997). A central question in the research of Groenvold et al. (1997) was the interpretation of patients through analysis of the results. Interestingly, the researcher states that quantitative and qualitative analyses are equally needed to realise the potential issues in a questionnaire.

#### 6.1.2 Practical implications

As aforementioned, this qualitative case study approach made comparisons between two groups of participants by way of two different methods: interviews and the self-reported analogous SF-12-item questionnaire. All interviewees shared similar characteristics in terms of age, diagnosis, the severity of the disease, similar conditions and symptoms. Two weeks later, these same interviewees filled out the self-reported questionnaires. As Kvale and Brinkmann (2009) stated, the choice between qualitative and quantitative methods depends on the type of question at hand. These researchers argued that quantitative methods are suitable for investigating individual personal aspects, and qualitative methods are more suitable for contextualised persons in social groups. Flick (2014) pointed out that it is important to specify the links between the relations that are studied, and the conceptual framework provided by the researcher to assess validity in qualitative research.

This research collected not only patients' points of view about the quality of care received while undergoing oncological treatment, but also quality attributes by way of the questionnaires to identify useful, reliable and valid key indicators. The patients' perspectives and points of view - the so-called subjective factors of patient satisfaction – could not be solely measured by a standardised questionnaire. This research focuses on the patient's perspective. The traditional system-related quality dimensions of structure-, process- and outcome parameters developed by Donabedian (1988b) will help to provide information about the quality of the relationship, doctor-patient-competences, and individual experiences. Quality management aspects, which are influenced by the quality of life, patient satisfaction, quality of care and cross-sectoral collaboration, must be considered as the basis of quality features of care-givers.

General systematic collation of interviews and questionnaire

Quantitative data analysis that uses numerical and graphical descriptive methods is, as Blaikie (2009) stated, used to measure tendencies and distribution. This research was designed in such a way that classification is a conceptual process (Denzin, 1978). Generated data was broken down from both the interviews and questionnaires into smaller pieces. These pieces were then brought together again in an innovative analytical manner. With quantitative data, the coding and categorising process is reduced to numbers which, after being summarised and interpreted, could be brought back to the social world of constructivism (Blaikie, 2009; Halfpenny, 1997). To be able to form conclusions following these methods, it was necessary that the content of interviews and questionnaires corresponded. Halfpenny (1997) argued that words in qualitative data and numbers in quantitative data are not fundamentally different.

#### Statement for a conjoint analysis

Questionnaires and interview surveys, when compared, help to paint a more comprehensive picture of QOL and PS. The question of whether the patients interpret the questions in the same way as the researcher does is an important consideration in this thesis. The interview was performed before the questionnaire so that the interviewee was not biased by ways of thinking alluded to in questionnaire categories to address this topic. This order also helped the patient with the questionnaire process; the questionnaire was easily understood because questions that required more discussion were raised during the interviews. The interviewer could ensure that the patient clearly understood key topics and thus could avoid misunderstanding. Unlike other studies which have amassed results derived from comparing interviews and questionnaires such as those by Greenhalgh and Meadows (1999) and Ware et al. (1995), this research was designed to concentrate on the relationship between PS and QOL to evaluate the influence on QOC for patients. The limitation of the chosen research design was that the research did not intend to use a purely quantitative or mixed-methods study (see limitations chapter for further explanations).

Furthermore, the results provide an intensive chart of patients' preferences during their treatment and are useful in the context of improving the patient-doctor-relationship and decision-making in outpatient units. Particularly important is the information regarding patients' expectations of and their perceptions about the quality of care they received when undergoing treatment in a new health care model.

# 6.1.2.1 Realisable recommendations that result from the research methodology, methods and findings

The researcher used constant comparison, as suggested by Goodrick (2014) in order to compare findings and interpret the gathered data. Yin (2009)'s proposed technique of triangulating the interviews and questionnaires was used to gain a rich and detailed understanding of patient situations, attitudes and behaviours. Mays and Pope (2000) describe triangulation as part of validity criteria. The triangulation of qualitative data from nodes and interviews within two patient groups with and without ASC did not constitute a mixed-methods approach because the researcher did not triangulate quantitative and qualitative methods. The questionnaire was transferred from a quantitative into a qualitative evaluation.

In this study, constant comparison and triangulation were performed with <u>interview questions</u>, the corresponding answers and <u>relevant nodes</u> on the one hand and the results of the <u>questionnaire</u> on the other hand. An additional comparison of both patient groups <u>with and without ASC was performed.</u> Additionally, the results of this research were compared with the key results of the <u>PASQOC study</u>. The underlined terms are discussed in the following sections.

#### 6.1.2.1.1 Interview questions

The fifteen interview questions portray the spectrum of the QOC in a single outpatient unit. The problem of patients who did not fully answer questions or gave different answers was reflected in qualitative, subjective interpretation and broad allocation of thematic nodes. The significant number of options of the chosen thematic nodes mirrors the aspects of the QOC extensively. The allocation of replies added to the variety of nodes reduced the bias caused by the researcher's subjective evaluation. In the wording, agreeing or rejecting answers needs to be evaluated in the overall context. Answering questions of the thematic complex "interpersonal" (questions a-c) did not reveal a trend regarding the QOC. The knowledge gained from this study yielded no statements about how many or which interview questions may be redundant or irrelevant.

#### 6.1.2.1.2 Relevant nodes

For each patient and node, the researcher gathered the rating scores in the original table and built sum-scores. Data was gathered from the intersections of nodes for good and bad valuation in the cross-table diagram. The evaluation of sumscores and frequencies of intersections achieves value from the interview questions on information regarding the oncological QOC. Groups of nodes with high or low evaluation rates were compared.

This relates on the one hand to nodes with high sum scores and high intersection rates (field A of the original and cross table) and on the other hand to nodes with low sum scores and low intersection rates (field C of the original and cross table). Within these groups A and C with high and low evaluation rates, the researcher examined the single node evaluation in relation to the questions from "a to o". That means, how many points receive an answer from the question ("a to o") in the respective node. These results were performed, compared and were brought in relation. Repeatedly observed similarities and differences illustrated new tendencies and provided the basis for interpretation and conclusion. Constant comparability between both groups increases the data validity with regard to the significance of the results of nodes and questions regarding the QOC. This will identify which nodes through thematically similar questions were only purely selectively answered – and thus can be excluded in future observations.

Juxtapositions and constant comparison of the gathered data were achieved through a sorted descriptive sum-score in the original table, an intersection for especially "good or bad" validation (cross diagram for "good and bad"), the determination of consistently high valuated questions with regard to the nodes from field A and C and the consideration of the assessment reaction of the corresponding patients. Nodes with high values and intersection grades for "good" reveal that a good QOC for the practice exists. This is mainly defined for the observed patients through nodes 12 (adequate treatment), 19 (patient activation), 27 (transparency and information). High priority valued and high interconnection for "good and for bad" are the nodes 7 (trust in the doctor), 19 (patient activation), 25 (recommend the organisation) and seem to be mainly distinguishing and indicative of the evaluation of QOC.

The nodes with especially low scores and low linkage for "bad" are supposed to be of little importance on the oncological quality of care and could be excluded in further studies. This affects nodes 4 (consolation) and 14 (cooperation). For further studies and optimisation in future, nodes 13 (alternative treatment), 14 (cooperation), 30 (far from practice personal conflicts), 31 (far from practice social aspects) seem to be not applicable because of the selective thematic and low scoring points. Regarding node 30 and 31 (far from practice social and personal conflicts), patients spoke sparsely and if they spoke then in conjunction with the expression for no need for psychological support. Patients, in general, did extremely occasionally express themselves on the subject. The nodes 26 (rush) and 29 (far from practice financial) are eliminated because of lack of allocation.

<u>In sum</u>, out of the 31 in total, nodes 4, 13, 14, 26, 29, 30, 31 should be excluded in further studies. For further research, a reduction of nodes is necessary to simplify

the tool and to identify the relevant nodes with greater importance. In this context, the researcher considered also reviewing fields B and C with lower scores. It must be shown whether these nodes might have in future a higher influence on other nodes or fulfil the criteria for "null" and should be excluded.

#### Critical comments:

The researcher presumed that if a patient has a high personal total score, often found in the upper third of nodes, this individual patient might tend to have a too good evaluation. With regard to the question that contributes generally for a too good evaluation, considering on the one hand the personal total score and on the other hand the particularly bad rating of the nodes of those patients, a patient with a high personal total score and low negative rating of nodes may also have a tendency for a too good evaluation. The literature mentioned the quality dimension model of Glatzer (1984)'s well-being paradox that focused on a patient's adaption in difficult situations for maintaining their level of well-being. The estimation of the QOC of the outpatient unit cannot be equated with the numerical value of nodes but can only be considered as a trend in comparison with other nodes.

#### 6.1.2.1.3 Questionnaire

In addition to the interviews, a questionnaire for evaluation of the QOL was completed. A generic questionnaire was chosen for more general information about the QOL and less information on therapy side-effects. For simplification of the evaluation and to aid the participants, instead of the complex and comprehensive quantitative SF-36, the more adapted short-form SF-12 was provided. Due to the small sample size of the study group and for better comparability with the qualitative interview, there was a qualitative evaluation of the self-administered questionnaire. The evaluation takes place in three main categories of health: physical, psychological and pain-related issues. The SF-12 questionnaire comprised different opportunities for answering; hence, a uniform scaling with 0 for poor and 1 for good; other questions are uniformly scaled 0 up to 4 points.

The evaluation of the questionnaire follows the qualitative valuation of the researcher to achieve comparability between the interview and questionnaire. The comparison of PS from the interviews and QOL from the questionnaire assessment presented that a higher QOL mainly supported higher patient satisfaction and vice versa. In the Non-ASC group, the themes of physical, psychological and pain from the questionnaire are evaluated considerably better than in the group with ASC. Therefore, it can be determined that patient satisfaction (based on the interviews) and quality of life (based on the questionnaires) are rated consistently. This affects

the voting behaviour of the entire group. Only a few patients show divergent behaviour of the total sum-score in the interviews in comparison to the sums of their questionnaire. In the ASC group are four out of five patients with a lower QOL and a discrepantly better interview rating. This could be interpreted that a poor QOL is associated with an understanding of good QOC despite bad conditions with a strong need on behalf of the patients for good oncological quality of care.

The individual semi-structured interview and the questionnaire complete each other regarding the evaluation of the oncological quality of care. The results show that the analogous SF-12 questionnaire is a useful addition. One comment on the category pain in the questionnaire from the themes is that only a few patients developed pain. This was caused by the fact that pain is a relatively rare complication of gastrointestinal cancer diseases. This may be different in other patient settings and tumour entities. Different evaluation of patients from the ASC group between questionnaire and interview help to reveal the patients' acceptance of the disease and the lack of willingness to recommend the institution. Therefore, the researcher considered a comparison of questionnaire and interview to receive indepth information about the valuations of QOL.

#### 6.1.2.1.4 Ambulatory specialised care

In practical terms, shortly after the implementation of the ASC in the single outpatient unit, at most, only a few changes to the oncological quality of care were obtained. It seems complicated for the new ASC model to improve the quality of oncological care in a medical practice which already met the targets of the oncology guidelines. Additionally, at that time, the ASC criteria did show only a few quality improvements as did already available studies (Klein et al., 2018), (Dengler & Cassens, 2018). Kaiser et al. (2017) stated that after one and a half years of experience in Bavaria the ASC implementation is work- and time-intensive but with potential for improvement.

Dengler, Walawgo, Baumann, and Cassens (2017) criticise the lack of clear regulations on who should get detailed information and the lack of suboptimal cooperation between a general practitioner and oncologist. Also, critical aspects are that the ASC and the oncology contract are not regulated for aftercare for patients or a measurement of patient-relevant endpoints. Thus, the implementation of new health care models should be focused on the patient's perspective as an important precondition for quality management aspects.

Recommendations that will improve upon current actions for ASC

The group with ASC gave poor results about concerns and fears, awareness of sufficient information about possible side effects, more need for additional psychological support and burdensome and stressful travelling to therapy and consultation hours. This could suggest a worse physical and psychological condition of the group of patients with ASC. On the other hand, this indicates a greater need for oncological care and support for the patients undergoing ASC.

The patients with ASC get to lower total scores in patient satisfaction interviews. The results of the QOL survey are still considerably lower from the group of patients with ASC. That means, patients with ASC have a moderately lower patient satisfaction rate than the Non-ASC group, but the quality of life is significantly much worse. Remarkably, four patients from the group with ASC demonstrate high levels of PS despite having drastically lower QOL. If this happens, (low PS and lower QOL) patients show a better acceptance and adaption of their disease and consequently a greater willingness for a better evaluation of the QOC.

In the group with ASC, the higher validation of node 2 (acceptance and support by the physician) is related to a patient's information about their disease, treatment options of therapy and information about treatment and alternative treatment as a basis for the compulsory and comprehensive introduction to the guidelines of the ASC. The questions regarding cooperation, professional exchange, and organisational coordination of appointments refer mainly to the priorities of the ASC concept and are persistently highly valued.

#### Recommendation and the key takeaway message from the ASC model:

The patients of the ASC group seem to particularly appreciate the compulsory requirements of the cooperative interdisciplinary treatment team and the intensive information about the concepts of the ASC. The apparent advantage of the comprehensive prior information means that it could be helpful also for patients without the ASC model to receive more complete explanations of the therapy and cooperative interdisciplinary treatment network of the oncological practice.

#### 6.1.2.1.5 Comparison with the PASQOC study

The results of this research tend to reflect the broad consensus of results from the quantitative PASQOC study. Kleeberg et al. 's' (2005) research found that "patient-provider-relationship, information on diagnosis and treatment options, and the facility setting" are the most important prerequisites for the recommendation of the institution. Regarding both studies, the key points are, on the one hand, doctors' personal, professional, communicative and integrative competence, and on the other hand, the quality and reliability of the organisational processes.

In contrast with the results of the performed study in the outpatient unit, the PASQOC study for several participating practices needs improvement in the area of "doctor-patient communication and organisation of care". The main aspects of nodes and interview questions in this study are thematically very similar to the results of the PASQOC study. This might be an indication that small-scale qualitative studies also could reproduce the results of a larger quantitative one. The current study points out only a few areas for improvement. As compared to the PASQOC study, the patients in this study expressed less desire for psychological support. The participants in this study mostly lived in rural regions and had close personal relationships with their families. Patients, therefore, benefitted from reliable support systems at home and were possibly influenced by the fact that there is sometimes less social acceptance in rural regions than in urban regions for psychological treatment. The lack of desire for psychological support could also have reflected good quality of oncological care of the unit by doctor and team.

Patients in this research noticed emotional distress and burden regarding the tumour diagnosis. However, unlike the results of the PASQOC study, these patients positively assessed aspects such as access to alternative information, shared-decision-making, and the doctor listens attentively. This is based on the most important precondition of patients being provided with in-depth and transparent information about their tumour diagnoses and the available therapeutic options. Despite the importance of having patients be truthfully informed about their diseases, openness about the gravity of the medical conditions could be quite shocking and painful to bear for some of the patients. These aspects, and not a lack of information, led to a lower value of the node "information about diagnosis". Highly negatively scored in the PASQOC study was the aspect "doctors having not enough time". In this research project, the theme "enough time" was given only sporadic approval and corroborated with other lower scored nodes. This indicates a negative assessment of the oncological QOC. This expressed from a patient's point of view the need and the expectation for more time and dedication. The doctor and team must discuss amongst themselves how to make more time and resources available for patients. However, for node 26 rush (too much stress and hectic), no one has made comments.

Patients indicated a need for more time with the doctor both in the PASQOC study and the current research project. This raises the question of to what extent the lack of time for involved patients generally is a symptom of overcrowded doctors' offices and excessive bureaucracy in the health care system.

#### 6.1.3 Limitations and opportunities

This research may have some limitations that the researcher identifies from the research context during the study. The approach was interpretative, subjective and depended on the researcher's personal choices and points of view. This study did not perform an in-depth analysis of the psychological and physical living situations of one single patient. However, every statement of patients was analysed systematically and determined by application to nodes, themes and questions. This led to an in-depth understanding and perception of participants. The project contributed knowledge through evaluation of statements about the validation of the QOC and the treating doctor and team in the single outpatient unit.

Patients in a rural area with gastrointestinal tumours under the criteria of ASC were included in the study. The inclusion- and exclusion criteria were defined and based on the demographic data that are relatively well mapped and representative, and specific for this region. In the outpatient setting, the framework in this research showed only minor differences for the study participants. Nevertheless, it cannot be assumed that patients answered the questions without the influence of disturbing factors. These disturbing factors are explained next.

A limitation could be in the criteria of the patient selection. Another limitation is the small number of participants and the poorly represented medical outcome. Also, the transferability of the results is problematic given the heterogeneity of patients, the inclusion and exclusion criteria of the chosen patients of the study, and the individual patient's behaviour of the routine-based oncological practice. The inclusion criteria for gastrointestinal tumours of the ASC included a larger number of heterogenic tumour identities, which can lead to imbalances in the study group. This means that the patients studied suffered from different GI tumours such as rectum, colon, pancreas. These different entities are in outpatient units too small for a representative number of study participants, and that could, therefore, lead to imbalances in the study group in case of too many various stages of tumour diseases.

Another restriction is the use of the questionnaire analogous to the standardised SF-12. The researcher implemented her survey with identical questions and a scoring system analogous to the interview questions. The aim was to compare and contrast the findings from interview and questionnaire for similarities and differences in answers from patients. This method did not use a validated questionnaire and could, therefore, be biased. The researcher strengthens her research with internal quality criteria of social research (see section quality criteria 3.4.4).

As mentioned, the answers of each patient during the interview were divergent in terms of length, taciturnity, deviating and avoiding answers. At this point, to reflect, the researcher decided consciously to take a step back to consider what way was best for further analysis. Subsequently, she decided to interpret and value the interview answers to emphasise their importance to the mentioned 31 nodes. Also helpful was the coding to mitigate a potentially emotional influence from the indepth interview.

In many cases, during the interviews, the patients express their deep sorrow and grief (see examples of the interviews). The researcher is not free from feelings and emotions; however, based on her experience and knowledge, at no time did this influence her objectivity. On the other hand, after carrying out the twenty different interviews, she felt, to a certain extent, more sensitive and empathic about the needs and concerns of tumour patients. In retrospective reflection, at the end of the study, the researcher felt inspired and motivated as well as competent and qualified for further studies in this field.

The researcher tried to reduce these limitations by building two equal groups with similar eligibility criteria. Another restriction of heterogeneity could be through reduction of one tumour entity, e.g. only colon or oesophagus cancer. Also, the comparison of an interview and questionnaire with identical questions reduced the bias. The lack of reliability and validity was offset through triangulation. Internal validity through triangulation of sources and transferability through interviews capture people's perspective and experiences in the context of process and findings. The limited time frame between the interview and questionnaire was chosen because of the severe illness and problems that may change a patient's perceptions. The difficult challenge of the high burden of a complex, severe disease of the patient should always require a restrained use of methods, time and mental stress.

To conduct the interviews, the researcher required a range of skills and expertise. The fact that the researcher was both integrated into the research process and part of the caring team, represented a potential conflict of interest. One potential bias in most qualitative studies is that the interviewer might bias the answers given in the interviews. Interviewee responses might show beliefs generated during the interview rather than pre-existing beliefs. Furthermore, it is almost inevitable that an interviewer transfers his or her existing attitudes and beliefs to the interviewee to some degree. To avoid this bias as much as possible, the researcher employed different strategies based on the detailed interviewer guide (see chapter methodology, Figure 8: Overview of the interview guide). In future studies, employing multiple interviewers could considerably increase the objectivity of the interview data.

The question of whether the results would differ if other interviewers had been employed cannot be answered with certainty. However, it is noteworthy that the study results displayed remarkable similarities to those of the PASQOC study. In addition to this, the results of the interviews were widely supported by the more objective questionnaire data and were therefore deemed by the researcher to be a sufficiently objective interpretation of reality.

It was also of immense importance that the participants felt comfortable during the interview and trusted the interviewer. However, the use of a questionnaire based on an analogous multiple time-tested validated questionnaire (SF-12) means the researcher has probably reduced this bias. Another possible conflict in the interviews was that the researcher could have misinterpreted patient responses or could have failed to ask sufficient details when patients were answering questions. In addition to this, the researcher was involved in providing healthcare services to the interviewees. This could have resulted in a conflict of interest.

This question of bias is addressed in detail in section 3.4.4 Quality criteria, section: Reliability and validity of the assessment. Specially trained nurses as co-workers (and not doctors) can carry out a major part of the documentation requirements. An opportunity can be for nurses to expand their traditional function in primary care with additional functionality to support patients.

The researcher considered that the application of the chosen interview and questionnaire might have burdened patients less and the questions and nodes from interviews might have correlated better to evaluate the QOC, but this research does not aim to replace a specific tool or to recommend another. However, the researcher points out the necessity to replace the comprehensive assessment questionnaires in oncology treatment.

At this point, it is impossible to predict the quality of a process. As Klein et al. (2018) pointed out, "informed consent" (meaning patients received information about diagnosis and treatment) is to be previously signed by patients before they start their medical treatment. However, this presupposes that sufficient information was provided and all questions were answered. There is no evidence that this conversation ever took place, respectively, and what level of scope and quality has been achieved. As Neuss et al. (2005) argued, these efforts are important and necessary but could provide limited insight into working oncologists on how good or bad the quality of their work has been.

Patients reported on the incisive and burdensome information about the tumour.

These aspects and not the lack of information lead to a lower reasonable valuation of the node "information about diagnosis". On the topic of "enough time" the patients gave less acceptance of this node as an expression of need and came only from a few patients as a wish for more time.

From the researcher's point of view, the results are encouraging. The results from this study may serve as a patient-centred tool to combine PS and QOL to enhance the QOC for patients in the outpatient setting. Also of interest are patients undergoing care under the new health care model of ASC, not forgetting the time- and work-intensive labour of the treating doctors and other participants.

Further studies are necessary on whether characteristics and relationships between PS and QOL on QOC in larger regions exist and how these influence each other.

#### 6.1.4 Alternative considerations

The use of comparative data, minimal standards, and benchmarking are key issues in the management of quality in health care. Therefore, the researcher demands an evaluation of the quality of care using regular surveys for continuous quality improvement (CQI). The method presented for the determination of the QOC could be used as a longitudinal comparison within the same outpatient unit or in multicentre studies. Such a procedure should be measured by the results of the existing quantitative study to monitor the quality.

The following contains an exemplary description with recourse on the literature review.

The study of Hermes-Moll et al. (2015) tests the feasibility of a questionnaire for measuring the QOC with 46 quality indicators. This is a quantitative multicentre study. Hermes- Moll stated in 2013 that Bauman and his WINHO institute tested and commented on these quality indicators in a peer-to-peer study in August 2013. The quality indicators, as mentioned above, focused only on process indicators and not on outcome parameters. Quality indicators are retrospective surveys. A feasibility study tested quality indicators in everyday practice, but different and inhomogeneous results and time-consuming processes lead to low information of data (less than 30 per cent).

The researcher concludes that the introduced method of quality indicators is not feasible for the implementation of a practical, prompt and easy to handle tool for evaluation of the quality of oncological care of one single outpatient unit. The research from Hermes-Moll et al. (2015) postulates valuable information on process

indicators. From the researcher's point of view, it provides the feasibility analysis for quality of care (Hermes-Moll et al., 2015) but only limited insights to working oncologists about the quality of their work.

Also of interest is the study to measure the quality of health care from the patient's point of view from Baumann et al. (2008). The results were presented from quantitative questionnaires from 147 participating outpatient practices and 15,272 patients nationwide in 2006 from the scientific institute of haematologists and oncologists in private practices (WINHO) in Cologne. An important element of this quality assurance approach is the consideration of medical treatment and patient-related outcome with the primary concept of the PASQOC study (Kleeberg et al., 2005). The results of the two studies of Kleeberg and Bauman differ in the furnishing of the premises. The waiting rooms had a good rating in the PASQOC but a poor rating for lack of magazines, journals and equipment in Baumann et al.'s (2008) research.

Both studies contained a suboptimal rating for information material and magazines and a critical validation for waiting times. However, it is noted that the applied survey items which had been used previously in many other studies, limits analyses of weaknesses of patient satisfaction with care.

From the researcher's point of view, the advantages of the results from her study are as follows: the interview enables individual, in-depth information and is transferable to the contents of the key nodes. The aim of the identified key nodes (doctor-patient-relationship, information on diagnosis and treatment options, quality of service and cooperation) is to concentrate on a practical, prompt and easy to handle but relevant tool for the evaluation of patient satisfaction but the method of the study is relatively complex. Also taken into account, as Baumann et al. (2008) suggest, was emotional aspects for a trusting relationship as well as the doctor-patient-communication.

As both studies from Kleeberg et al. (2005) and Baumann et al. (2008) are relevant for the current research, the researcher has to make a selection for the decision of the chosen reference for the PASQOC research. Arguments for the PASQOC, on the one hand, are the overall assessment to estimate the QOC from both patient satisfaction and quality of life. Kleeberg et al.'s (2005) study identifies some highly problematic issues that are the basis for the actual interview survey. The current study depicts that the development of a qualitative tool should be useful and easily available as well as for the practice to create its own. It remains to be seen

whether this approach, which depends on Donabedian's (1988) structure-processoutcome parameter of quality management will lead to an improvement.

Another possible application could be an up-to-date review of the QOC with a qualitative tool that takes place in a multicentre setting. The participating medical practices could frequently communicate their qualitative data with a central institution. Medical practices must compare the results of their self-evaluations with those of other medical institutions. Longitudinal quantitative studies could potentially be coupled with qualitative studies for this purpose.

The studies mentioned above of Kleeberg et al. (2005) and Baumann et al. (2008) are both relevant for the current research. However, the researcher decided to follow the PASQOC approach. The main reason for this was that the PASQOC uses both PS and QOL to evaluate QOC. Issues highlighted in Kleeberg et al.'s (2005) study are the basis for the actual interview survey. The researcher of this study aimed to develop a qualitative tool that should be effective and easily available. As Sale et al. (2002) point out, the qualitative observation of PS and QOL presented a snapshot and need, unlike quantitative indicators, long-term retrospective experience. Such a tool could be used for comparison of PS and QOL and must ideally work in the same way in other medical practices under the same conditions and lead to the same results.

Tüllmann (2015) sees the term satisfaction as being associated with the fundamentally different circumstances of individuals, who can be either satisfied or dissatisfied. When aspects of quality of life are modified, this leads to increased satisfaction or dissatisfaction. Tüllmann's (2015) method was to assign patient statements regarding their healthcare experiences into categories such as satisfaction, quality of life, good life, happiness, and well-being. When doing this, Tüllmann (2015) only looked at word counts with sum-scores rather than forming a scale to rate the meaning associated with the patients' statements. It is here where the researcher of this thesis diverged from Tüllmann's (2015) method. To gain a deeper understanding of patient statements, the researcher assigned every patient answer with a value to emphasise the importance with which patients endowed particular topics.

Quality of life researcher Cummins (1996) states that subjectively perceived satisfaction leads to higher personal satisfaction scores because people usually feel good about themselves. Consequentially, perception of satisfaction is influenced by other external factors than just those that affect PS; it seems impossible to predict the relationship between external conditions and subjective PS.

This idea has been touched upon in quantitative studies with large sample sizes, which show that not only are external factors such as the oncological "hard" endpoints like response rate and progression-free survival the basis for oncological QOC but also QOL and PS. This study does not focus on the "hard" endpoints of oncological therapy, as these are not quantitatively determinable in single outpatient units because of the small number and heterogeneity of patients. The established instruments and items as above mentioned could not be exploited to take a neutral approach. The comparison of both groups of participants requires a balanced methodological approach. Consequently, the researcher began looking for other quality aspects which could evaluate PS in healthcare and determine what influences patients' opinions and behaviour when they undergo treatment.

This study aims to qualitatively determine whether patient satisfaction and quality of life can be used to evaluate the patient oncological quality of care in a single outpatient unit. This research demonstrates that quality of life and patient satisfaction research are essential when asking patients to report on aspects of their experience of care and their needs. This work shows a new approach to the topic. If the results from the patient-reported health-related QOL and PS reveal relevant limitations or deterioration, this could indicate a concrete need to improve QOC. The term quality of care is multifaceted and intangible. Its many indirect indicators include disease-, treatment-, and symptom-related factors. A qualitative approach adopts the perspective that multidimensional profiles cannot be evaluated only by quantitative questionnaires because of the difference between standard or generic and illness-specific procedures. Also, it is reasonable to assert that written formulations about patient behaviour in questionnaires might not always represent the patient's true feelings. In many studies, patients express satisfaction with the care that they have received even though their medical prognoses are not good. An interview format allows patients to speak more spontaneously and openly about their healthcare experiences.

The study also examines how patients in a single oncological outpatient unit in Germany interpret the QOC in the previous healthcare model as compared to the care provided by the new ASC model.

#### 6.1.5 Summary of discussion

PS reflects the perceptions of structure- and process quality aspects. QOL refers to physical, psychological, social and functional well-being as aspects of the outcome. Structure-, process- and outcome are an essential aspect of QOC. However, PS is also influenced by the current psychological and physical condition of patients. This supports, according to the current literature, the assumption that the

combined examination of both PS and QOL is essential for the evaluation of the QOC.

PS and interview questions highlighted aspects which are regularly important for patients. There are a few nodes which were evaluated particularly 'good' by some patients and particularly 'bad' from others. These especially useful differentiated nodes seem to reflect the QOC sensitively. These nodes are related to: "trust in the doctor", "patient activation, e.g. involvement and participation in treatment decisions", and "the willingness to recommend the organisation". Thus, these themes are particularly important to evaluate the quality of structure and processes and the adherence of doctor and team. The results of this study indicate that PS with the treating physician is a significant factor of QOC. Patients' lives and care depend on the doctors. For care to be effective, patients must place their trust in these doctors. This is more accessible when the relationship between patient and doctor is excellent.

Determining QOL in this study and the allocation to the main categories (pain, psychological and physical well-being) does not allow drawing differentiated conclusions. Therefore, the question arises as to whether the sketched-out tool is useful to describe the structure- and process quality; but the aim given, to evaluate the indirect assessment of the outcome, remains relatively open. Consequently, the question remains how far the QOL as an outcome parameter in this setting could be evaluated differentiated and more effectively. The comparison of QOC of patients of different medical practices can still only serve as a limited statement of the QOC because of, on the one hand, the heterogeneity of patients with different tumour status and on the other hand the environment of the practices differing from each other.

The comparability of the QOC between different medical units and the medical outcome of oncological patients would presuppose a far-reaching and comprehensive analysis and description of baseline criteria. QOC is an endpoint of medical treatment and is influenced by many preconditions including: age, gender, personal, social, cultural and financial conditions of patients; nature of tumour diagnosis and stage, tumour burden, degree of metastasis, period of tumour disease since diagnosis, dosage of already given tumour-specific therapy and response rates.

For comparison of the QOC between different medical practices as a quality feature, all aspects had to be considered. However, this would go beyond the scope of practicability. Important issues such as tumour burden and degree of metastasis could not be realised as scientifically valid in everyday practice. The QOC relates

to the entirety of all oncological patients of medical practice. This contrasts with trials that are conducted with defined in- and exclusion criteria. More meaningful for the evaluation of the QOC seems the longitudinal comparison of QOL as part of the same medical practice under the conditions of clearly defined changes. The longitudinal comparison between medical practices is only possible to a limited extent due to the difficulty to specify a deviation from the QOC under the changing conditions of the environment of the medical unit or the quality of the medical treatment.

Triangulation is used to clarify and strengthen the questions and answers from interviews by identifying and ruling out meaningful key nodes that are important and relevant to match the QOC. Using a constant comparison that shows reproducible results taking into account the quality criteria of qualitative research, the researcher evaluates the multitude of information from interview questions according to a valuated coding schema. The qualitative analysis of the multiple information gained from the semi-structured interview represents a significant difference and a proposed advantage towards a quantitative approach, which must be limited to a reduced number of endpoints. This qualitative approach allows oncological medical practices to estimate their quality of oncological care, based on their limited number of patients. Interestingly, the qualitative study, in comparison with the quantitative PASQOC reference study, shows very similar outcomes. Both this study and the PASQOC study identified "recommending the medical practice, patient-provider relationship, information on diagnosis and treatment, quality of service and cooperation with other medical units" as being especially noteworthy.

The addition of the qualitative evaluation of a quality of life questionnaire could point out discrepancies in single cases between PS and QOL, provide references for acceptance of disease and adaption or rejection respectively of quality of care. Questions and nodes identified as being of particular importance, with others less meaningful, can be implemented through a tabular sorting of scoring sums regarding questions, nodes and patients and their respective intersections for "good=applicable and agreeing" versus "poor=not applicable and rejecting". Several nodes could be excluded for simplifying the tool to evaluate QOC.

The willingness of patients to assume psychological support even with poor quality of life scores was very low. The researcher justified this with the close family relationship in rural regions; in urban settings, the result could be quite different. The application of combining interview and questionnaire works, and if the results from patients reporting PS and QOL show relevant deterioration or restriction, this could be meaningful information for concrete help and support if necessary.

The mandatory requirements for cooperation, in-depth information and the interdisciplinary treatment under ASC was highly appreciated by the participating patients and could be a distinct advantage for the oncological practice. This can be derived from the collected data and results that could lead to a possible improvement of quality of care due to the individualised applicable tools from PS and QOL in order to integrate patient perspectives. Furthermore, it can be assumed that the concept can be transferred to other settings, and there appears to be a strong probability that a flexible tool can be developed in further studies. The findings of the study are relevant for understanding a patient's specific needs and expectations because the tool provides a prompt analysis and estimation of the individual medical practices. For improvement of the comparability of the results, it could be helpful that all interviewers should receive a comprehensive and standardised training course. An opportunity can be for nurses and other team members to increase their traditional role in primary care with further functionality to help patients.

The data highlighted that patient satisfaction with the physician is a critical and important factor of quality of care because patients prefer to trust their doctors with whom they feel their lives and care depend, and the relationship between patient and doctor meets the demands for healing and caring. In summary, a great patient-doctor relationship is fundamental for their care and associated with increased compliance and continuity of care. To assess the current status of QOC among cancer patients in an outpatient unit by qualitatively identifying the key factors that determine PS and QOL with QOC seems a practical way of achieving greater relevance and benefit for patients.

As aforementioned, this study aims to qualitatively determine whether PS and QOL can be used to evaluate the QOC in a single oncological practice. Also, to examine how the QOC under the oncology contract compares to the QOC under the ASC model, as perceived by the patients. The results of the study reveal the answers to these research questions. Through in-depth analysis and constant comparisons, relevant and reproducible key factors could be identified. Interestingly, the findings are very similar to the results of the quantitative PASQOC reference study. Based on these results, the comparison with and without ASC shows only minor differences. This indicates no relevant improvement for quality of care for oncological patients undergoing the new ASC model in comparison with the current oncology contract model.

### 7. Conclusion

Improving oncological QOC requires a systematic understanding of the factors that influence patient health outcomes. This thesis examined how PS and QOL impact QOC. This case study looked upon the complex factors that influence care as well as the role played by patients and providers in the health care system. As outlined in the introduction chapter, this research pursued two main questions: The first question was whether it is possible to assess the QOC of patients in one single outpatient unit by evaluating QOL and PS. The second question was whether and how patient evaluations of QOL and PS change with the new German model of Ambulatory Specialised Care (ASC).

The survey showed that important themes correspond between both groups with and without ASC. The following thematic nodes seem to be of greater relevance for good QOC: trust in the doctor, the involvement and participation of patients in treatment decisions (the so-called patient activation node), the availability of information about possible side effects and on-going procedures, acceptance of diagnosis, transparency and information about examination and organisational procedures, quality of structural and organisational service, and patient willingness to recommend the organisation. Three nodes appear to be particularly good differentiated between good and bad QOC: trust in the doctor, patient involvement in treatment, and whether a patient would recommend the medical organisation. Interestingly, these themes correspond to those identified in the referenced quantitative PASQOC study.

The findings of the QOL questionnaire did not indicate corresponding tendencies between the thematic categories of physical-, psychological well-being, and pain. In most cases, patient reports of PS in the interviews corroborated the QOL reported in the questionnaires. Most patients reported better PS than QOL. This might suggest that these patients had accepted their diseases and better appreciated the QOC. Therefore, the results indicate that it is possible to assess the QOC of patients in one single outpatient unit by evaluating QOL and PS. The qualitative analyses of PS and QOL are a basis for a reliable tool to determine the QOC for a small number of cases in a single outpatient unit.

Only slight differences could be found between the patient evaluations of QOC provided by the ASC and oncology contract models to answer the second research question. That may be an advantage for patients through comprehensive information regarding ASC structure, and processes. The new ASC model on QOC appears to have only a minor impact for oncologists who previously worked under the conditions of the oncology contract.

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Previous extensive quantitative studies have shown that there is a relationship between QOC, PS and QOL. The quantitative, multicentre PASQOC study of Kleeberg et al. (2005) determined that PS and QOL are key components of QOC in outpatient oncology practices. In this thesis, a qualitative design was selected to examine PS, QOL and QOC. The questions arise as to whether the major quantitative points, as shown in the PASQOC study, are more important than other aspects and to what extent these relevant aspects can be answered qualitatively. This research used semi-structured interviews to evaluate PS. The interview answers were allocated by the researcher to 31 thematic codes, based on the coding rules developed by Kuckartz (2007). These nodes and sub-nodes were compared with one another. It was then determined how many of the sorted nodes were associated with the highest or lowest level with each interview question.

QOL was evaluated with a questionnaire analogous to the standardised SF-12 questionnaire. The questionnaire was qualitatively evaluated and focused on generating data for three categories: physical well-being, psychological well-being and pain. Patient interview scores were then juxtaposed with their questionnaire scores to compare PS and QOL. Once the comparison of PS and QOL had been completed, the researcher compared the results of the ASC group with the non-ASC group. The results of this analysis could be used to develop a practical tool that physicians could use to assess QOC in their single outpatient practices. An overwhelming majority of patients evaluated PS in the interviews and QOL from the questionnaires concordantly. Only a few patients gave deviating valuations. As a result of this research, a better valuation of PS and a lower valuation of QOL can be interpreted as a better acceptance and adaption of the disease.

The research topic of this thesis is focused on the patient-centredness requirements, patient perspectives and their needs as a perspective for oncological health research and the society. The topics examined in this research are currently of significant importance, given the rapidly changing conditions of the German health care system. This research examines how to reliably assess PS and QOL as factors that contribute to QOC. PS and QOL can be seen as structure-, process-, and outcome quality parameters based on Donabedian's (1988) quality management model. Due to the heterogeneity and small number of patients in the single outpatient practice being studied, this research adopted a qualitative approach. A quantitative analysis must be limited to a lesser number of quality indicators and could, because of the small size of the sample group, fail to be statistically significant.

The current study examined the opportunities for single outpatient units to evaluate their own oncological QOC rapidly and independently. This could lead to continuous quality improvement in medical practice and improve the treatment being provided for cancer patients. Also, it is beneficial for cancer patients and for the oncological outpatient unit being studied to determine the effectiveness of therapy under changing conditions of the health care system. This research strategy explicitly focused on the needs of patients with life-threatening and often long-term illnesses because these patients require continuous, comprehensive care that is based on their personal needs, perceptions and expectations.

Donabedian's research has played a decisive role in health care studies and has demonstrated, like Bullinger (1991), that QOC is a multidimensional construct. Using quantitative studies, Aaronson et al. (1993) developed the cancer-specific EORTC QLQ-C30 questionnaire (European Organisation for Research and Treatment of Cancer QLQ-C30). Ware et al. (1995) built on the EORTC questionnaire and developed the generic, standardised SF-36 questionnaire. Kleeberg et al. (2005) then combined the SF-36 questionnaire with a questionnaire of their own in a quantitative PASQOC study, which sought to identify patient needs and perceptions. Sale et al. (2002) argued that quantitative methods are not capable of obtaining sufficient information from the patient's perspective.

However, quality aspects of care from a patient's point of view by comparing semistructured interviews and equivalent questionnaires were not examined in closer detail in a single outpatient clinic. This qualitative research can be used to evaluate the QOC as a significant contribution to knowledge promptly. In this study, key factors were defined regarding the key topics of PS and QOL of the PASQOC study (Kleeberg et al., 2005). This study examined patients with gastrointestinal tumours undergoing chemotherapy treatment in a single medical outpatient unit.

In the German healthcare system, specialised outpatient care and hospital care have traditionally been complementary service areas with clearly separate functionality. The oncology contract, which was Germany's oncological treatment model up until the introduction of ASC, was established to ensure quality improvement for engaged and responsible doctors nationwide. As an alternative to inpatient treatment, the oncology contract was implemented to support the outpatient supply of cancer patients in statutory ambulatory care. The Federal government required, by law, cooperation and interdisciplinary discussion between specialist physicians on tumour boards through multidisciplinary cancer team-meetings. Inpatient care and hospitals were excluded from the oncology contract. In the context of the shift into outpatient care under §116b, these hospitals can treat patients with rare and severe diseases under the ambulatory specialised care

model. Based on this paragraph, the new ASC model was implemented. The implementation of ASC for oncological tumour diseases began with gastrointestinal cancers. It proposes to open hospitals for ambulatory care within the scope of ASC and foster the cooperation of medical specialists and approved hospitals.

The ASC model aims to overcome sectoral borders and improve the QOC by strengthening the competition between in- and outpatient care. The ASC guidelines stipulate that patients be provided with comprehensive information about the existing QOC, service, treatment and the new range of services available to them. As other authors have described, the doctor-patient- relationship, support, coordination of care and transparency of information play a special role in general practice, especially for chronically ill patients.

The Federal Joint Committee only defined structural quality as being a prerequisite for outpatient and inpatient care under ASC. However, the aim to guarantee high-quality care should be based on patient-relevant outcomes. For ambulatory oncologists, the new ASC healthcare model differs only slightly from the former oncology contract. Under the ASC model, more emphasis is placed on specific structures. For example, patients are treated by an interdisciplinary team of accredited doctors who participate at weekly tumour boards and offer interdisciplinary consultation hours. Those patients who do not have access to the oncology contract are those that would especially profit from ASC. It is pertinent to consider whether national law and the regulations of the leading healthcare associations are primarily focused on the QOC or whether they focus instead on political and economic circumstances.

This question highlights the importance of increased transparency in the acquisition of data about QOL and PS. This transparency should lead to an improvement in quality of treatment and consequently to better health outcomes and could be used in the face of structural changes to the health care system. In health care research, the combination of qualitative and quantitative methods in a single case study is practised and accepted. However, this type of combination should not be reduced to one specific method or design because of the distinct size and range of questions, which can be approached with both qualitative and quantitative methods.

As Kleeberg (1998) stated, the comparability of the outcome is unfeasible when only based on quantitative QOL results. Medical processes, treatment and symptom burden, are expressions of the medical outcome. Baumann et al. (2008) stated that it is necessary to study in-depth QOL and PS together to gain a more holistic picture about patient experiences, their perspectives and personal needs.

However, their studies were still quantitative rather than qualitative. Greenhalgh et al. (2013) conducted a qualitative study that examined oncologists and their patients. The aim was to explore and optimise the patient-related-outcome and focused only on patient-doctor-communication. Velikova et al. (2008) also emphasised the value of qualitative research for clinically assessing QOL in oncology. Their study focused mainly on medical functions.

Pascoe (1983) determined that PS is an emotional reaction to the structures, processes and outcomes of service and is subjective rather than objective. The majority of the literature reported more satisfaction from patients who have had a strong and long relationship with their physicians (Cleary & McNeil, 1988). Influencing factors such as bad conditions, mood and depression could all affect patients' everyday situations. Klinkhammer-Schalke et al. (2012) stated that comorbidity and progression of the disease influenced the therapy treatment process. The conceptual framework of Lis et al. (2009) suggested a relationship between cancer and fatigue. In addition to this, Zapka et al. (2003) emphasised the role that health care systems may play in improving the oncological QOC because patients are threatened by financial issues and the availability of social resources.

Kleeberg et al. (2005) and Pascoe (1983) did a great deal of qualitative research on QOL. The result of this effort has been the development of code- and keywords in this thesis. The knowledge gained in this research could potentially be a tool for the future on the extent to which a single outpatient unit can evaluate and control its quality assurance.

In this thesis, the researcher's subjectivity constituted a potential validity threat. This limitation could be rectified in future studies by performing more research in several medical practices. The results of the studies could then be compared.

The reason the researcher chose a qualitative inductive approach for this research is that it allowed her to focus on individual patient experiences, feelings and perceptions. The patient's point of view is significant when evaluating QOC. The research approach combined interviews with questionnaires because questionnaires alone are not individualised enough to provide information that accurately represents the patient's point of view (Velikova et al., 2008). Questionnaires are also not the best way to identify the supply needs of a specific group of patients (Mallinson, 2002). The questionnaires and interviews were both based on Donabedian's (1988) quality management aspects. While by no means identical, they both treated comparable topics. The results of the interviews and questionnaires were combined to form conclusions about the overall status of QOC.

In the semi-structured interviews used to evaluate PS, patients were allowed to answer in a spontaneous and unfiltered manner. This occasionally led to incomplete, or short dialogues that limited the researcher's ability to glean meaning from patient answers. For this reason, the researcher allocated the interview answers to 31 thematic codes with a scale system developed by the researcher. The coded data from individual statements were assessed and grouped into broader categories, the so-called nodes, and thematic blocks: interpersonal, medical and organisational. The nodes and sub-nodes were compared with one another, and the sorted nodes were associated with the highest or lowest level of answers in the interviews.

Furthermore, QOL was evaluated with the use of a questionnaire analogous to the quantitative, standardised SF-12 questionnaire. For comparison purposes, the questionnaire developed for this research was qualitatively evaluated. Questions were grouped into three categories: physical well-being, psychological well-being and pain. Answers were scored based on a scale developed by the researcher. Each patient's interview scores, which evaluated PS, were compared with the scores of the questionnaires, which evaluated QOL. In both the ASC and non-ASC groups, PS and QOL were compared.

The results of this study show that the implementation of the new ASC health care model only led to minor changes in QOC. These changes were limited to patient access to information, doctor-to-doctor-cooperation and interdisciplinary treatment. This lack of change could be attributed to the fact that the outpatient unit being studied worked under the oncology contract, which already provided a high-level of care for patients.

According to the findings, eight of thirty-one thematic codes can be seen as indicators of high oncological QOC. These include: trust in the doctor, the involvement and participation of patients in treatment decisions (the so-called patient activation node), the availability of information about possible side effects and on-going procedures, acceptance of diagnosis, transparency and information about examination and organisational procedures, quality of structural and organisational service, and patient willingness to recommend the organisation. Three nodes emerged that were of particular relevance to QOC: trust in the doctor, patient involvement in treatment, and whether a patient would recommend the medical organisation. Among the fifteen interview questions, all of them proved to be highly relevant.

In future, 7 of the 31 codes can be excluded. This applies to lower-level evaluated thematic codes and lower correspondence of bad ratings of other codes. Nodes which were only evoked in response to thematically narrow questions or not evoked in interview questions could also be excluded. The significance of the remaining sixteen thematic codes without any tendency must be evaluated in further studies.

The results of the QOL questionnaire did not show correspondence or deviation between the categories physical well-being, psychological well-being and painlessness. It was, therefore, not possible to develop a statement that determines how these physical and psychological issues interact. Only a few patients expressed pain. This was caused by the fact that pain was a relatively rare symptom for the gastrointestinal cancers of the study subjects. This may be different in other settings where patients suffer from diverse types of cancer. The patients predominantly concordantly evaluated PS in the interviews and QOL in questionnaires. Only a few patients gave deviating valuations. In these rare cases, PS was better valued than QOL. This was observed mainly in the ASC group. A better valuation of the PS can be interpreted as better acceptance of and adaption to disease and possibly a greater willingness to give a better evaluation of the QOC.

The possible limitations of this research included the following: In a few cases, patients provided vague or off-topic answers to interview questions. Consequently, the answers could not be related to any thematic codes and were given the rating of "null". It remains unclear if the focus of the interview question is potentially not suitable or not relevant. In sporadic cases, patients judge an explicit negative valuation. The observation of "too good ratings" has already been identified as a problem in other studies (Baumann et al., 2008; Herschbach, 2002; Kleeberg et al., 2005). Herschbach (2002), for example, speaks of the well-being paradox, stating that patients with severe chronic diseases tend to report a better QOL than healthy people. It is also sometimes the case that patients report positively on their situations so long as the doctor-patient-relationship exists. It could also be argued that too good a rating reflects an adaptation of patients, who wish to be overly positive and friendly toward their teams and doctors.

Another limitation depends on the subjective and interpretative scaling system from the researcher's point of view. The small sample size and under-represented medical treatment outcomes could also be limitations. However, the small number of patients in practices is always a limitation because researchers cannot form broad generalisations. The results of such studies are, therefore, always interpretive. The results of this research were not intended to be generalisable; however, some of the themes that are discussed might be applicable in other contexts.

Heterogeneity due to the broad inclusion criteria for patients is an issue for the transferability of the results. However, the qualitative tool that the researcher aimed to develop in this research should be able to be used by other researchers, who would come to similar conclusions. One disadvantage of this study is that it did not study the so-called hard endpoints. The qualitative evaluations of PS and QOL in this study were not compared with quantitative results of medical outcomes such as response rate, duration of response or overall survival. This type of comparison is occasionally performed in multicentre studies.

This study examined the practical and theoretical implications of a qualitative evaluation of QOC in a single medical practice. Occasionally, it was observed that patients tended to provide different or inaccurate answers to detailed interview questions. However, precisely, this problem can be addressed through weighted evaluation by thematic codes. The research results, while fruitful, lead to the following conclusions and recommendations for future studies:

Such research processes would profit from interview coaching for team members. This could lead to better comparability for a longitudinal observation in every single practice and between different practices. A qualitative evaluation of the QOC in a single practice is not in competition with quantitative observations of quality indicators in large patient pools. The qualitative approach with a small number of patients has the advantage of being relatively easy to conduct and of producing rapid results.

This qualitative approach will allow medical practices to estimate their own oncological QOC. This study showed similar outcomes to those of the quantitative PASQOC study. Both studies revealed that factors especially important to QOC were the patient's willingness to recommend the medical institution, the patient-provider-relationship, information on diagnosis and treatment options, quality of service and cooperation.

Very few patients, even those with poor QOL scores, desired psychological support. This could be because the patients did not live in urban settings, but rather where friends and family provide a great support network. Furthermore, it is reasonable to assume that informed patients who benefit from a close doctor-patient-relationship may suffer less from psychological burdens. Patients responded positively to the ASC implementation of interdisciplinary treatment that keeps the patient informed. This should be remembered in other oncological practices that seek to improve the provided QOC. In general, however, it seems that participation in ASC only slightly improved QOC.

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The results of this study indicate that PS with the treating physician is a significant and crucial factor of QOC. Patients' lives and care depend on the doctors. For care to be effective, patients must place their trust in these doctors, and it is made easier when the relationship between patient and doctor is good. This qualitative evaluation of QOC could be of high relevance to patients. By understanding the factors that contribute to PS and QOL, outpatient units could strive to create conditions that improve QOC.

The results of this thesis could be further examined in future studies. Having multiple outpatient units evaluate their own QOC by way of the methods discussed in this thesis could provide additional results that could enhance the validity and reliability of this approach. Additional studies could highlight the relevance of specific questions and thematic codes. Such an approach could also feasibly be used in a more extensive multicentre study. This could be performed quantitatively with focus on quality indicators and many patients. This quantitative information would then be combined with qualitative research on the QOC of the participating practices.

This study focused on the analysis of the QOC of a single outpatient practice and was based on the needs and perceptions of individual patients. The study did not focus on the individual optimisation and supply of single participating patients. Future studies could focus very specifically on the in-depth analysis of individual patients and could be related with the three thematic blocks of the interview questions (interpersonal, medical and organisational) to evaluate the PS and of the questionnaire to evaluate the QOL. In this way, questions about the extent of a patient's psychological burden and whether the need for psychological support is affected by the doctor-patient-relationship could be explored in more detail.

Finally, a practical qualitative tool should lead to comparable results, and its evaluation should be associated with a lesser burden on patients. This study examined whether ASC is beneficial for patients. The comprehensive information provided for ASC patients appreciated patients under the ASC model as well as patients under the interdisciplinary treatment model. A system should be put into effect in which patients who are not qualified for ASC also receive comprehensive information about treatment.

To further improve the ASC model, future research should evaluate relevant endpoints and outcome parameters, which took place two years after the implementation of the ASC. The author of this study also recommends that outpatient units that provide ASC routinely evaluate the QOC that they provide. These follow-ups would contribute to the continuous improvement of ASC implementation and would be advantageous for patients.

#### Summary

This research qualitatively evaluates QOC in a single outpatient unit. The outcome in terms of medical outcome for incurable patients means longer life and a good QOL. Individual life elongation cannot yet be fully evaluated, but a good response to therapy gives reason to hope for an extension of life. Good QOL consists of physical and psychosocial well-being aspects. QOL and PS surveys can evaluate these aspects. The QOC can be assessed through the collection from outcome parameters as well as objective and subjective patient-reported outcome parameters from QOL and PS.

The results of Kleeberg et al.'s (2005) PASQOC study suggested that QOL and PS are favourably influenced when a good medical outcome is achieved. QOL and PS have been comprehensively examined in multicentre quantitative studies. The results of these large quantitative studies, however, cannot be observed in a single outpatient unit with a small sample of patients. This is because the illnesses and personal requirements of oncological patients are remarkably diverse, and there is far too small a sample size in an outpatient unit to come to any significant conclusions about these different disease characteristics.

This research aims to determine to what degree a qualitative method for evaluation of QOL and PS can draw conclusions on the QOC. This research contributed new knowledge with a qualitative approach evaluating the oncological QOC because, as yet, there is little detailed knowledge on the qualitative and subjective experience of patients with gastrointestinal cancer diseases undergoing ASC in a single outpatient clinic. As the literature review demonstrated, previous studies have already documented that we can use PS and QOL quantitatively to evaluate QOC. However, it has not yet been determined how we can qualitatively use PS and QOL to evaluate the QOC provided to oncological patients in a single outpatient unit. A robust and reliable method to promptly estimate the QOC provided to small numbers of patients in single outpatient units has not yet been established.

This study identified three key themes as being central to QOC: doctor-patient-communication, comprehensive patient information, and organisational procedures. Interestingly, these themes correspond to those identified in the quantitative PASQOC study. The findings of the QOL questionnaire did not indicate corresponding tendencies between the thematic categories of physical-, psychological well-being, and pain. Possibly, a comparison of single answers from patients (of PS and QOL) could lead to additional relevant knowledge.

In most cases, patient reports of PS in the interviews corroborated the QOL reported in the questionnaires. Even in the ASC group, some patients reported experiencing better PS than QOL. This might suggest that these patients had accepted their diseases and better appreciated the QOC. Further studies are recommended based on the findings of this research that could develop a qualitative reliable, practicable, rapidly available tool for estimating the oncological QOC in a medical practice.

From the findings of this thesis, practical conclusions can be drawn:

# What impact does the new model of ASC have on the QOC for patients and is this impact beneficial?

It would be helpful for outpatient units to integrate qualitative tools (interviews and questionnaires) in everyday practice to improve QOC. This research is the first step towards semi-structured interviews and questionnaires that could be frequently used to assess QOC.

For a comparison of the research findings, it is necessary to apply uniform parameters and methods. This applies, in particular, to the QOL questionnaire. The SF-12 questionnaire is a valid instrument to measure outcome parameters. To provide any additional information from a quality of life questionnaire seems only applicable if a discrepancy exists in patients evaluating their QOL concerning PS. The QOL pertains to outcome parameters; in contrast, the interview comprises structure- and process parameters primarily. This gives strong support to a combination of PS and QOL to evaluate the QOC. However, further studies should not only focus on the outcome- but also on structure- and process parameters. Future studies should also focus on a higher number of patients suffering from diverse types of cancer. This could help determine what disease-specific factors influence PS. Such studies could be possible in general, multicentre settings. Quantitative indicators could be compared with qualitative QOC data from all participating units. The quantitative outcome results gained from this method would form a benchmark, which could be used in other medical practices. The qualitative tool would provide researchers with an in-depth understanding of the QOC in each single outpatient unit, which could be compared with the QOC provided by other oncological practices.

Only minor differences could be found between the patient evaluations of QOC provided by the ASC and oncology contract models. That may be an advantage for patients in terms of comprehensive information regarding ASC structure, and pro-

cesses. The impact of the new ASC model on QOC appears to be minimal for oncologists who previously worked under the conditions of the oncology contract. Given the fast-changing conditions of the German health care system and the implementation of ASC to adopt routine-based follow-up processes of outcome parameters based on QOC, these follow-ups will contribute to continuous quality improvement - which will be beneficial for tumour patients.

Relevant to a patient's willingness to recommend the medical practice are doctorpatient-communication, patient information, and good organisation procedures. The results of this study indicate that key aspects of medical treatment rather than amenities and premises are essential for the QOC.

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# 9 Appendix A: Literature Review

# 9.1 A1 Search strategy and databases

### 1. Topic area" Quality of life in oncology"

Search string: Medline in PubMed

(Quality of Life[MeSH] OR (Indicator[title/abstract] AND ("Quality of Life"[title/abstract] OR "QOL"[title/abstract]))) AND (measure\*[title/abstract] OR Questionnaires[MeSH] OR assessment[title/abstract] OR Interviews[MeSH] OR instrument[title/abstract]) AND (Outpatients[Mesh] OR Ambulatory Care[Mesh] OR Health-related quality of life[Mesh] OR quality of life in oncology[Mesh]OR Quality of life in cancer[MeSH]

Results: 240 hits (09.09.2017)

Search string: Embase

((quality-of-life.sh. OR (Indicator.ti,ab. AND (Quality-of-life.ti,ab. OR QoL.ti,ab.))) NOT Drug\*.sh) AND (measure.ti,ab. OR questionnaire.ti,ab. OR interviews.ti,ab. OR assessment.ti,ab. OR instrument.ti,ab.) AND ((outpatient or ambulatory-care or ambulatory-specialised-care)) NOT ((hospitalization OR nursing-home OR primary-healthcare).sh. NOT ((outpatient or ambulatory-care or home-for-the-aged or home-care).sh. or home-care-services.ti,ab. or home-care-agencies.ti,ab. or home-nursing.ti,ab. or community-healthnursing.sh. or long-term-care.sh. or family-caregivers.ti,ab.))

Results: 225 hits (25.07.2017)

Searchstring: CINAHL

(TI (Quality-of-life)) OR (AB (quality-of-life)) OR TI Qol OR AB Qol) AND (TI Indicator OR AB Indicator) AND (TI measure\* OR AB measure\* OR MH Questionnaires OR TI assess- ment OR AB Assessment OR TI instrument OR AB instrument) AND (MW outpatient OR (MW (ambulatory specialised care)) OR (MW (Interviews)) OR (MW (cancer care))

Results: 220 hits (09.09.2017)

### 2. Topic area" Patient satisfaction in oncology"

Search string: Medline in PubMed

(Patient satisfaction[MeSH] OR (Indicator[title/abstract] AND ("Patient satisfaction"[title/abstract] OR "Patient satisfaction oncology"[title/abstract]))) AND (measure\*[title/abstract] OR Questionnaires[MeSH] OR assessment[title/abstract] OR Interviews[MeSH] OR instrument[title/abstract]) AND (Outpatients[Mesh] OR Ambulatory Care[Mesh] OR Ambulatory Specialised Care OR Patient satisfaction cancer therapy[Mesh] AND (Patient-reported-outcome[Mesh]

Results: 115 Treffer (16.03.2017)

Search string: Embase

((patient-satisfaction.sh. OR (Indicator.ti,ab. AND (patient-satisfaction.ti,ab. OR patient satisfaction oncology.ti,ab.))) NOT Drug\*.sh) NOT well-being\*.sh)AND (measure.ti,ab. OR questionnaire.ti,ab. OR interviews.ti,ab. OR assessment.ti,ab. OR instrument.ti,ab.) AND ((outpatient or ambulatory-care or ambulatory-specialised-care)) NOT ((home-care OR nursing-home OR primary-healthcare).sh.

Results: 136 hits (17.03.2017)

Search string: CINAHL

(TI (Patient-satisfaction)) OR (AB (patient satisfaction oncology)) OR TI patient satisfaction) AND (TI Indicator OR AB Indicator) AND (TI measure\* OR AB measure\* OR MH Questionnaires OR TI Interview OR AB Interviews OR TI instrument OR AB instrument) AND (MW outpatient OR (MW (ambulatory specialised care)) OR (MW (Interviews)) OR (MW (cancer care))

Results: 9 hits (16.03.2017)

### 3. Topic area" Quality of care in oncology"

Search string: Medline in PubMed

(Quality of oncological treatment[MeSH] OR (Indicator[title/abstract] AND ("Quality of care"[title/abstract] OR "Quality of oncological care"[title/abstract]))) AND (measure\*[title/abstract] OR Questionnaires[MeSH] OR assessment[title/abstract] OR Interviews[MeSH] OR instrument[title/abstract]) AND (Outpatients[Mesh] OR Ambulatory Care[Mesh] OR Ambulatory Specialised Care OR Patient related quality of care[Mesh] AND (Quality of life and care in oncology[Mesh] AND (Outcome in oncology) AND (output in oncology[Mesh])

Results: 158 hits (16.03.2017)

Search string: Embase

((Quality of oncological care.sh. OR (Indicator.ti,ab. AND (Quality of oncological treatment.ti,ab. OR QOL care oncology.ti,ab.))) NOT Drug\*.sh) NOT well-being\*.sh)AND (measure.ti,ab. OR questionnaire.ti,ab. OR interviews.ti,ab. OR assessment.ti,ab. OR instrument.ti,ab.) AND ((outpatient or ambulatory-care or ambulatory-specialised-care)) NOT ((home-care OR nursing-home OR primary-healthcare).sh.

Results: 113 hits (17.03.2017)

Search string: CINAHL

(TI (Quality of care oncology)) OR (AB (Quality of treatment oncology)) OR TI quality of care cancer) AND (TI Indicator OR AB Indicator) AND (TI measure\* OR AB measure\* OR MH Questionnaires OR TI Interview OR AB Interviews OR TI instrument OR AB instrument) AND (MW outpatient OR (MW (ambulatory specialised care)) OR (MW (outpatient unit)) OR (MW (outpatient unit quality cancer care))

Results: 83 hits (16.03.2017)

### 1. Topic area" Quality management in oncology "

Search string: Medline in PubMed

(Quality management of oncological treatment[MeSH] OR (Indicator[title/abstract] AND ("Quality management of oncological care"[title/abstract] OR "Quality management in oncology"[title/abstract]))) AND (measure\*[title/abstract] OR Questionnaires[MeSH] OR assessment[title/abstract] OR Interviews[MeSH] OR instrument[title/abstract]) AND (Outpatients[Mesh] OR Quality management of Ambulatory Care[Mesh] OR Ambulatory Specialised Care OR Quality management of Patient related quality of care[Mesh] AND (Quality management of Quality of life and care in oncology[Mesh] AND (Outcome in oncology) AND (output in oncology[Mesh]

Results: 58 hits (16.03.2017)

Search string: Embase

((Quality management of oncological treatment.sh. OR (Indicator.ti, ab. AND (Quality management of oncological care. ti, ab. OR Quality management in oncology. ti, ab.))) NOT Drug\*.sh) NOT well-being\*.sh) AND (measure. ti, ab. OR questionnaire.ti, ab. OR interviews.ti,ab. OR assessment.ti,ab. OR instrument.ti, ab.) AND ((outpatient or ambulatory-care or ambulatory-specialised-care)) NOT ((home-care OR nursing-home OR primary-healthcare).sh.

Results: 36 hits (17.03.2017)

Search string: CINAHL

(TI (Quality management of oncological treatment)) OR (AB (Quality management of treatment oncology)) OR TI quality management of cancer) AND (TI Indicator OR AB Indicator) AND (TI measure\* OR AB measure\* OR MH Questionnaires OR TI Interview OR AB Interviews OR TI instrument OR AB instrument) AND (QM outpatient OR (QM (ambulatory specialised care)) OR (QM (outpatient unit)) OR (QM (outpatient unit quality cancer care))

Results: 28 hits (16.03.2017)

# 2. Topic area "Ambulatory specialised care (ASC)"

Search string: Medline in PubMed

(Ambulatory specialised care [MeSH] OR (Indicator[title/abstract] AND ("Quality of ambulatory specialised care"[title/abstract] OR "ambulatory specialised care in oncology"[title/abstract]))) AND (measure\*[title/abstract] OR Questionnaires[MeSH] OR assessment[title/abstract] OR Interviews[MeSH] OR instrument[title/abstract]) AND (Outpatients[Mesh] OR Ambulatory Care[Mesh] OR Ambulatory Specialised treatment OR Patient related ambulatory specialised care[Mesh] AND (Quality of ambulatory specialised care in oncology[Mesh] AND (Outcome in oncolog y) AND (output in oncology[Mesh]

Results: 58 hits (16.03.2017)

Search string: Embase

((Ambulatory specialised care.sh. OR (Indicator.ti,ab. AND (Quality of Ambulatory specialised oncological treatment.ti,ab. OR Ambulatory specialised care oncology.ti,ab.))) NOT Drug\*.sh) NOT well-being\*.sh)AND (measure.ti,ab. OR questionnaire.ti,ab. OR interviews.ti,ab. OR assessment.ti,ab. OR instrument.ti,ab.) AND ((outpatient or ambulatory-care or ambulatory-specialised-care)) NOT ((home-care OR nursing-home OR primary-healthcare).sh.

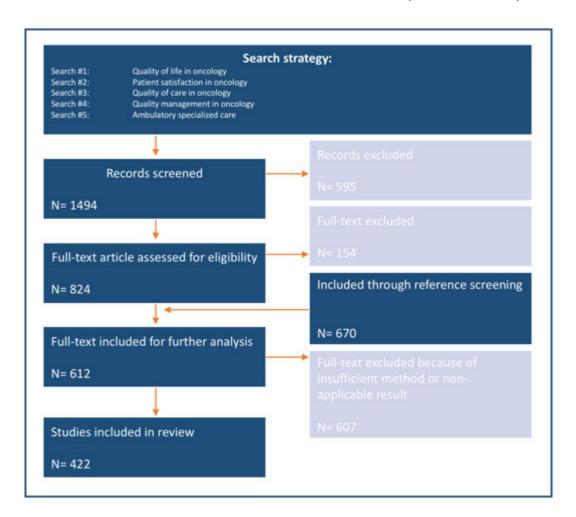
Results: 6 hits (17.03.2017)

Search string: CINAHL

(TI (Ambulatory specialised care oncology)) OR (AB (Ambulatory specialised care of treatment oncology)) OR TI quality of Ambulatory specialised care cancer) AND (TI Indicator OR AB Indicator) AND (TI measure\* OR AB measure\* OR MH Questionnaires OR TI Interview OR AB Interviews OR TI instrument OR AB instrument) AND (MW outpatient OR (MW (ambulatory specialised care)) OR (MW (outpatient unit)) OR (MW (outpatient unit quality cancer care))

Results: 9 hits (16.03.2017)

FIGURE 3: SEARCH STRATEGY AND SELECTION PROCEDURE (OWN DRAWING)



# 9.2 A2 Towards defining the terms

TABLE 42: DEFINING THE TERMS (OWN SOURCE)

Dividing the literature into themes of:	Distinct themes from the literature are assigned in:	Theoretical and empirical literature:
The concept of quality of life in cancer patients	Definition of the term	Most popular approach: key author in the field, landmark study
The concept of patient satisfaction in cancer patients.	Search strategy	Allows integration of theoretical and empirical (research)literature:
		Background articles Empirical articles Instrument related articles
The concept of quality of care in cancer patients	Inclusion and exclusion criteria	The themes are related to the literature:
		Applying methodologies, using different instruments, determinants of the concept
The concept of ambulatory specialized care	Data synthesis	
The concept of quality management aspects in cancer patients	Model of the term	
	Early studies, pivotal role, focusing on it's relationship	

# 9.3 A3 The concept of quality of life

TABLE 43: STUDIES ON RELATIONSHIP BETWEEN QUALITY OF LIFE DATA AND GENERIC TERMS

Author (s)	Study name	Type of cancer / instruments/Journal	Main findings / conclusions
(Bullinger , 2000)	Erfassung der gesundheitsbezogenen Lebensqualität mit dem SF-36-Health Survey	Generic questionnaire SF 36	Comparison, quantitative study. Development of supply concepts. Analyse supply structure and needs in health care sector distress was a significant predictor of survival in lung cancer.
(Bullinger , 2008)	Assessing health related quality of life in medicine. An overview over concepts, methods and applications in international research	Generic	An overview over concepts, methods and application
(Bullinger , 2016)	Zur Messbarkeit von Lebensqualität	Generic	Evaluation of life quality measurement concepts
(De Santis & Steininger , 2014)	Lebensqualität – quality of life (QoL)	Generic and disease specific instruments	Patient reported outcome
(Fischer, Krämer & Klose, 2015)	Revelance of quality of life as a quality indicator in guideline development	Description of quality indicators on the German context	Patient reported outcome, study taking into account the QoL and not factors of morbidity and mortality
Kenneth Charles Calman, 1984)	Definitions and dimensions of quality of life	Measurements of quality of life	Evaluation of quality of life positive aspects
(Küchler & Berend, 2011)	Lebensqualität in der Onkologie	EORTC questionnaire	Study of quality of life in quality management models. Concepts. Development of a life quality questionnaire
(Pakhale et al., 2011)	Combining both generic and disease-specific properties	Quality of life questionnaire	Development of the McGill COPD

TABLE 44: STUDIES ON RELATIONSHIP BETWEEN QUALITY OF LIFE DATA AND CANCER IN PATIENTS WITH GASTROINTESTINAL CANCER

Author (s)	Study name	Type of cancer / instruments/Journal	Main findings / conclusions
(Blazeby et al., 2005) )	A prospective comparison of quality of life measures for patients with oesophageal cancer	Assessing QOL with FACT and EORTC questionnaire	Determine which instruments are appropriate in which contexts.
(Borras et al., 2001)	Compliance, satisfaction, and quality of life of patients with colorectal cancer receiving home chemotherapy or outpatient treatment: a randomised controlled trial	Comparing given chemotherapy at home and in the outpatient unit	Improvement of compliance and satisfaction with treatment
(Byrne, Griffin, Blazeby, Conroy, & Efficace)	Health-related quality of life as a valid outcome in the treatment of advanced colorectal cancer	EORTC disease specific tools	Measurement of HRQL in clinical research but disease specific

TABLE 45: STUDIES ON RELATIONSHIP BETWEEN QUALITY OF LIFE DATA, PATIENT SATISFACTION AND QUALITY OF CARE

Author (s)	Study name	Type of cancer / instruments/Journal	Main findings / conclusions
(Baumann et al., 2008)	Patient satisfaction with office-based oncology practices		To measure the quality of health care from a patients point of view
(Kleeberg et al., 2008)	Patient satisfaction in outpatient cancer care: a prospective survey using the PASQOC questionnaire	PASQOC questionnaire	A prospective survey to identify the needs of patients Comparison with other practices
Essink- Bot, Macken- bach, & van der Maas, 1997)	Health-related quality of life: an indicator of quality of care?	Framework	Evaluation of the applicability of health status measures as quality of life indicators

# 9.4 A4 The concept of patient satisfaction

TABLE 46: THE CONCEPT OF PATIENT SATISFACTION

Author (s)	Study name	Type of cancer / in- struments/Journal	Main findings / con- clusions
(Baumann, Nonnen-ma- cher, Weiß & Schmitz, 2008)	Patient satisfaction with care in office- based oncology practices	Journal article	Patient perspective which influenced the quality of care that is provided
(Bleich, 2009)	How does satisfaction with the healthcare system relate to patient experience?	Bulletin of the World Health Organisation	External factors that patient satisfaction with health care influenced than experience of care
(Bruera et al., 2001)	Patient preferences versus physician per- ceptions of treatment decisions in cancer care	Journal of clinical on- cology	Younger patients pre- fer a more collabora- tive decision making
(Crow et al., 2002)	The measurement of satisfaction with healthcare	Systematic review of the literature	Expectations and your need of patient satisfaction
(Dona- bedian, 1966)	Evaluating the quality of medical care	Journal The Milbank memorial fund quarterly Review	Quality improvement or detecting weak points in health care processes
(Elkin, 2007)	Desire for information and involvement in treatment decisions	Journal of clinical on- cology	Cancer patients' preferences the physicians' perceptions
(Fitzpatrick, 2006)	A structured review of patient-reported measures in relation to selected chronic conditions, perceptions of quality of care and carer impact	National Centre for Health Outcomes Development, Uni- versity of Oxford A structured review	The importance of specific issues of patient's experiences of care and satisfaction External factors that patient satisfaction with health care influenced than experience of care
(Goldzweig et al., 2009)	Expectations and level of satisfaction of patients and their physicians: concordance and discrepancies	Journal Psychosomatics	Concordance and discrepancies Expectations and needs of patients. Re- lationship among pa- tient-doctor-commu- nication
(Kleeberg et al., 2005)	Patient satisfaction and quality of life in cancer outpatients: results of the PASQOC study	Journal Support Care Cancer	Patient-doctor-relationship is extremely important for patient satisfaction

(Lis, Rodegh- ier, Grutsch & Gupta, 2009)	Distribution and deter- minants of patient satisfaction in oncology with a focus on health related quality of life.	Journal BMC Health Services Research	Provide and overview of existing literature on patient satisfaction in oncology
(Möller- Leimküler et al., 2002)	Determinanten der Patientenzufriedenheit: behandlungsbezogene und klinische Variablen, subjektives Krankheitskonzept und Lebensqualität	Journal Fortschritte der Neu- rologie· Psychiatrie	Doctor-patient-com- munication and joint decision making a key element for quality of care
(Sitzia et al., 1997)	Patient satisfaction: a review of issues and concepts	International Journal of Nursing Studies A review	The expected nominal and experienced actual status define and interpret the idea of relevant determinants of satisfaction related to demographic and psychosocial features
(Ware, 1983)	Defining and measuring patient satisfaction with medical care.	Evaluation and program planning	Provides several features in a special patient satisfaction questionnaire (PSO), to represent the health care provider and the service they delivered, based on technical and interpersonal skills of the doctor.

# 9.5 A5 The concept of quality of care

TABLE 47: THE CONCEPT OF QUALITY OF CARE

Author (s)	Study name	Type of cancer / instruments/Journal	Main findings / conclusions
Blanchard, C. G., Labrecque, M. S., Ruckdeschel , J. C., & Blanchard, E. B. (1990)	Physician behaviors, patient perceptions, and patient characteristics as predictors of satisfaction of hospitalized adult cancer patients.	Journal of Cancer	Process elements: physician behaviors and patient perceptions as characteristics of satisfaction the patients perceived.
Brook, R., McGlynn, E., & Cleary, P. (1997)	Quality of health care. Part 2: Measuring quality of care.	The Journal of Cancer	Death as a single outcome parameter
Donabedian, A. (1966).	Evaluating the quality of medical care	Book: The Milbank memorial fund quarterly	Evaluation of health services. Dimension of quality
Gesell, S. B., & Gregory, N. (2004).	Identifying priority actions for improving patient satisfaction with outpatient cancer care.	Journal Nurse Care Quality	Outcome of care are the results of changes. Waiting- times as a structural parameter
Lohr, K. N., & Schroeder, S. A. (1990)	A strategy for quality assurance in Medicare	New England Journal of Medicine	desired health outcomes and current professional knowledge
Sandoval, G., Levinton, C., Blackstien- Hirsch, P., & Brown, A. (2006).	Selecting predictors of cancer patients' overall perceptions of the quality of care received.	Annals of Oncology	Outcome represents the effects of care on the health status of patients and influenced the health outcomes
Zapka, J. G., Taplin, S. H., Solberg, L. I., & Manos, M. M. (2003)	A Framework for Improving the Quality of Cancer Care	Journal of Cancer Epidemiology Biomarkers & Prevention	Several types of health care outcomes as an indicator of quality of care

# 9.6 A6 The concept of quality management aspects

TABLE 48: THE CONCEPT OF QUALITY MANAGEMENT ASPECTS

Author (s)	Study name	Type of cancer / in- struments/Journal	Main findings / con- clusions
Al-Abri, R., & Al- Balushi, A. (2014)	Patient survey as a tool towards quality improvement	ОМЈ,	QM Tool for patient satisfaction and quality of life to im- prove quality of care
Auras, S., de Cruppé, W., Diel, F., & Geraedts, M. (2014)	Qualitätsmanage- ment-Einführung	Gesundheitsökonomie & Qualitätsmanage- ment	Organisational and treatment processes towards the continuous quality improvement
Baumann, W., Busch- mann-Mai- worm, R., & Schmitz, S. (2012)	Qualitätssicherung und Qualitätsindi- katoren.	Der Onkologe	Quality indicators. Standardised quantitative data consisting on specific quality criteria based on patient satisfaction questionnaires and outcome parameters
Chassin, M. R., & Galvin, R. W. (1998)	The urgent need to improve health care quality	Jama	focus on the com- munication and de- cision making from patient perspectives
Donabedian, A. (1988)	Quality assessment and assurance: unity of purpose, diversity of means.	Inquiry	Def. of quality: structure in which care occurs, the pro- cess of care and the outcome attributes of care appears,
Dröschel, D., Stendera, M., & Im- kamp, U. (2017)	Analysen, Evaluation im Versorgungsmanagement	Versorgungsmanage- ment in der Praxis des Deutschen Gesund- heitswesens	Focused on three main perspectives in quality management which are significant for the necessary richness of the perspective and a comprehensive evaluation
Gourdji, I., McVey, L., & Loiselle, C. (2003).	Patients' satisfaction and importance rat- ings of quality in an outpatient oncology center.	Journal of nursing care quality	CQI for oncological patients using reliable and measurable key indicators

Hensen, P., & Hensen, G. (2010)	System-und subjekt- bezogene Perspekti- ven von Zertifizie- rungsver-fahren in Gesundheitseinrich- tungen	Gesundheitsökonomie & Qualitätsmanage- ment	Enlarged the sub- ject-related perspec- tive focusing of qual- ity of relationship- competences-pa- tient experiences.
Maxwell, R. J. (1984)	Quality assessment in health.	British Medical Jour- nal (Clinical research ed.	Suggest six dimensions of quality
Wild, C., & Patera, N. (2013)	Measuring quality in cancer care: over- view of initiatives in selected countries.	European journal of cancer care	Different quality management as- pects in oncology

# 9.7 A7 The concept of ambulatory specialised care

TABLE 49: THE CONCEPT OF AMBULATORY SPECIALISED CARE

Author (s)	Study name	Type of cancer / in- struments/Journal	Main findings / con- clusions
Bredart, A., Coens, C., & Aaronson, N. (2007)	Determinants of patient satisfaction in oncology settings from European and Asian countries: preliminary results based on the EORTC IN-PATSAT32 questionnaire	Eur J Cancer Questionnaire	Quality management improve ambulatory care
Degen, C., Möller, D., & Schlech- ter, C. (2014)	Patientenzufriedenheit bei onkologischen Erkrankungen	Das Gesund- heitswesen	ASC can represent a quality feature for the oncological treatment
Erhart, P. M., & Czi- hal, T. (2015)	Ambulante Versorgung	Medizinökonomie	Patient experiences and patient satisfac- tion are determinants of process quality in ambulatory care
Gill, T. M., & Feinstein, A. R. (1994).	A critical appraisal of the quality of quality of-life measurements.	Jama	qualitative research in the literature which represent the way cli- nicians and patients perceive is under-rep- resented
Jaeckel, & Da-Cruz. (2015)	Ambulante spezi- alfachärztliche Ver- sorgung	Market access & health policy	Quality features lead to improvement of structure and process at the interface of in- and outpatient care
Klakow- Franck, R. (2014)	The relevance of quality of life for the work of the Federal Joint Committee	Z Evid Fortbild Qual Gesundhwes	Innovative processes like ASC can added value in health care systems
Kripalani, S., LeFevre, F., Phillips, C. O., Williams, M. V., Basaviah, P., & Baker, D. W. (2007)	Deficits in communication and information transfer between hospital-based and primary care physicians: implications for patient safety and continuity of care	Jams	cross-sectoral collab- oration and interface issues between in- and outpatient care are rare and may af- fect patients' care

Orlowski, U. (2004)	Ziele desGKV-Modern- isierungsgesetzes (GMG)*.	Medizinrecht	Structure and process quality parameters – an interdiscplinary approach
Stiel, S., Joppich, R., Korb, K., Hahnen, M., Elsner, F., Rossaint, R., & Rad- bruch, L. (2009)	Problems and deficits in the transition from in- patient and outpatient care of cancer patients.	Der Schmerz	Quality features

# 10 Appendix B: Methodology

TABLE 50: BENEFITS AND DRAWBACKS BETWEEN GENERIC AND ILLNESS SPECIFIC PROCEDURES (OWN DRAWING)

	Benefits	Drawbacks
Generic procedures	<ul> <li>Good comparison</li> <li>Wide range of target groups</li> <li>It appears that there is an influence of medical interventions in different areas of life</li> <li>Influence of comorbidity and unspecified interventions will be revealed</li> </ul>	<ul> <li>Poor sensitivity and no clinical relevance in case of changes</li> <li>Not a focus on the important theme</li> </ul>
Illness specific procedures	<ul> <li>Good sensitivity</li> <li>Better differentiation within diseases</li> <li>High plausibility</li> </ul>	<ul> <li>Disadvantage in reliability</li> <li>Not comprehensive</li> <li>No comparison between illness specific diseases</li> </ul>

TABLE 51: COMPARISON BETWEEN QOL AND QOC (OWN DRAWING)

Aspect	QoL	QoC
Philosophy	<ul> <li>Relating to the person</li> <li>Focusing to the needs of the whole person</li> <li>Personalized care</li> </ul>	<ul> <li>Related to the illness and disease</li> <li>Focusing on patient</li> <li>Institutionalized care</li> </ul>
Definition	- Perpetual state	- Temporal condition
Theory	- Holistic	- Structural
Focus	- Outcomes based	- Structured based

TABLE 52: MAJOR PHILOSOPHICAL PARADIGMS IN SOCIAL RESEARCH (BASED ON GUBA & LINCOLN

Paradigm	Positivism	Post-positivism	Critical Theory	Interpretivist/ constructivist
Ontology	Hidden rules, "real" reality	Imperfect "real" reality	Reality is not real and performed by society	Reality is created by individuals in groups
Epistemology	Reliable and valid tools as quality criteria	Critical tradition and findings can be true	Subjectivist	Meanings and perceptions of human beings,  Events and activities
Methodology	Verification of hypotheses	Falsification of hypotheses,		
Method	Quantitative What works?	Experimental, qualitative	How can I change this?	Qualitative, How and Why

SEE Table 7: COMPARISON OF DIFFERENT INTERVIEW TYPES ACCORDING TO FLICK (2014)

Criteria	Standardized Interview	Semi- structured Interview	Expert Interview	Narrative Interview	Problem centred interview
Openness to the issue	Focused on standardized questions	Focused on open questions	Focused on the expert less interest on the interviewees	Focused on participants to ask and remember their experiences in the context of biographical research	Focused on biographies of different groups of people
Structuring of the issue	Guidelined questionnaire	The interview guide mentions several topic areas and participants can answer freely	Using semi- structured interview guides	Narrative questions generated	Interview guide as basis and narrative interview
Domain of application	Hypotheses	Not hypothesis confirming	Knowledge of expert from the institution	Biographical courses	Group discussion
Problems carrying out the method	Missing the personal point of view of participants	Interpretative not for biographical processes suitable	Only special knowledge of the expert and how to find the right expert	Time consuming narrators given much time to tell their stories, cultural problems of narration	Only subjective viewpoints linked to qualitative content analysis
Limitations	Summary of objective features, only data measuring aspects	Biased by the interviewer and interviewee	Representing a group not a single case. Definition of expert is unclear	Only reduced of narrative experience of participants	Includes group discussions and biographical method as a second and additional step

# SEE FIGURE 8: Overview of the Interview guide

1. Introduction

- Let me introduce myself...
- This interview aims to collect information about...
- The questionnaire will be followed two weeks later

2. Opening

- First of all regarding the general condition
- Questions of expectations of treatment, main concerns and estimated outcome during treatment

3. Specific questions

- I. Internal aspects
  - Interpersonal aspects:
     with regard to the atmosphere and patient-doctor-relationship
- II. Patient medical information
  - Medical aspects:
     treatment options, information of diagnosis and psychological support
- III. Accessibility of care and treatment environment
  - Organisational aspects:
     Coordination and cooperation with other medical institutions, appointments and recommendation

4. Demographic information

- Could you provide me some information about: age, family and social status, ...
- Words of parting and showing appreciation for the participant

TABLE 53: COMPARISON OF DIFFERENT QUESTIONNAIRE TYPES GENERIC AND DISEASE-SPECIFIC

	Advantage	Disadvantage
Generic term:	<ul> <li>Good comparison for a wide population application</li> <li>Influence of medical intervention and shows different areas of life</li> <li>Influence of comorbidity and unspecific interventions is revealed</li> <li>E.g.:</li> <li>Sickness Impact Profile (SIP)</li> <li>Nottingham Health Profile</li> <li>Spitzer Index</li> <li>Short-Form 36 (SF-36) + SF (12)</li> <li>World Health Organisation (WHOQoL-100 or WHOQoL-bref)</li> </ul>	<ul> <li>Generally less sensitive for clinical relevance</li> <li>Potentially no focus on the subject area</li> </ul>
Disease related:	<ul> <li>Better sensitivity</li> <li>Differentiation better within a disease</li> <li>Only those aspects may be adopted that are relevant</li> <li>E.g.:</li> <li>EORTC QLQ C 30</li> <li>FACT-G (Functional Assessment of Cancer Therapy)</li> <li>RSCL (Rotterdam Symptom Checklist)</li> </ul>	<ul> <li>Worse reliability</li> <li>Not comprehensive</li> <li>Comparison of different diseases and conditions not possible</li> </ul>

TABLE 54: ATTACHMENT I

#### Attachment I:

#### Declaration and Agreement about Informed Consent and Data Protection



#### Research Project:

Towards the Quality of Care for Oncological Patients: an Evaluation of a New Approach to Contribute New Knowledge

#### **Declaration:**

I confirm that I have informed the interviewee about the purpose of the study, the data collection, explain the details of this agreement about data protection, and obtained his or her agreement

- · The interviewee agrees that the interview will be recorded and scientifically analyzed.
- After finishing the recording he or she can ask for erasing single parts of the interview from the recording.

#### For assuring data protection, the following agreements are made:

- The recording of the interview will be stored in a locked room and in passwordprotected storage media by the interviewer or supervisors and erased after the end of the study or after five years at the latest.
- Only the interviewer and the members of the study team will have access to the recording for analyzing the data.
- For analyzing the data, the recording will be transcribed. All personal details, names and locations mentioned by the interviewee will be anonymized in the transcript as far as necessary.
- In addition the recording can be used for this doctoral study and for publication in a professional journal, it is guaranteed that identification of the interviewee will not be possible.
- The interviewer or the supervisors of this study holds the copyright for the interviews.
- The interviewee may take back his or her declaration of consent completely or in parts at any time without any drawbacks.

Ruth Anna Weber	
(Researchers signature, date)	

#### TABLE 55: ATTACHMENT II

#### Attachment II:

#### Informed Consent

#### Interviewee:

Name:

#### Informed consent of the interviewee (please tick as apporopriate)

- · Herby I confirm that, according to a survey of the University of Gloucestershire, I will be available for an interview for improving the quality of care.
- . I am informed, by content, methods and aim of the study project.
- . The aim of the project is as a result of the interview and questionnaire of your patient satisfaction and quality of life aspects to gain new knowledge of quality of oncological care in an outpatient unit.

#### The interview focuses on:

· Several issues related to coordination and cooperation between the teams of doctors, and other medical institutions.

#### I am informed that:

the participation in the interview and questionnaire is voluntary, the interview can be interrupted at any time without penalty or loss of privileges. I am free to continue or several questions can be in parts unanswered.

- · In additon, I do not suffer any disadvantages if I withdraw my participation.
- . In a short term after the interview, arising issues or emerging conflicts can discussed with the oncological team and/ or the treating oncologist.
- · All personal details, names and locations mentioned by the interviewee will be anonymized in the transcript as far as necessary.
- The recording of the interview will be stored and only members of the study team will have access to the recorded data

#### Hereby I explain myself

- · I agrees that the interview will be recorded and scientifically analyzed.
- For analyzing the data, the recording will be transcribed.
- In addition the recording can be used for this doctoral study and for publication in a professional journal, it is guaranteed that identification of my personal data will not be possible.
- The interviewer or the supervisors of this study holds the copyright for the interviews

Ruth Anna Weber		
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(Researchers signature, date) (Participants signature, date) TABLE 56: ATTACHMENT III

#### Attachment III:

#### Introduction (Interview for patients after informed consent)

This interview aims to collect information about the quality of care for cancer patients in an outpatient unit. We ask you to agree to an interview of twelve questions. The interview will be followed up one week from now with a structured questionnaire. We will provide you with a detailed information sheet outlining the reasons for data protection and the content of the interviews. If you have granted informed consent, we will start with the interview:

#### Opening: First of all regarding your general condition:

- a) What do you expect of your treatment at this medical practice?
- b) What outcome(s) do you hope will result from the completion of your treatment at this medical practice?
- c) What are your main concerns and fears relating to your situation?

#### I Internal aspects

#### (outcome and operational indicators)

- d) Do you think you would be <u>sufficiently well-informed</u> about your disease and treatment options?
- e) How well did we explain your diagnosis? How did you feel when given your diagnosis?
- f) How easy is it to speak with your doctor in a relaxed atmosphere?
- g) Do you feel that your doctor <u>listens</u> <u>attentively</u> to your problems and takes them <u>seriously?</u>

#### II Patient education and information

#### (operational indicators)

- h) How well have you <u>understood</u> the various treatment options available to you and the severity of your illness?
- How much have you been <u>included</u> in the decision-making process and realisation of the therapy?
- j) Do you feel that you have been <u>sufficiently informed</u> about the possible side effects of your therapy?
- k) To what extent do you require additional psychological support?

#### III Accessibility of care and treatment environment

#### (structural indicators)

- I) How well do you feel that the doctors treating your cancer disease reach out to other medical institutions on your behalf?
  - (cooperation and business exchange)
- m) How did you find the scheduling, especially the ease of making appointments when you needed them and the waiting time at external medical institutions? (coordination of appointments)
- n) How <u>burdensome and stressful</u> are the traveling distance to chemotherapy and consultation hours associated with your cancer?
- Would you <u>recommend</u> our medical practice to friends and relatives if they suffered from cancer?

# TABLE 57: RESEARCH ETHICS APPROVAL



#### UNIVERSITY OF GLOUCESTERSHIRE -RESEARCH ETHICS APPROVAL

Please ensure you have read the University of Gloucestershire Research Ethics Handbook of Principles and Procedures before completing this form (see, http://insight.glos.ac.uk/ResearchDevelopment/Documents/Research%20Ethics%20Handbook%20final%20Nov%2010.pdf )

To be completed by the researcher/s and supervisor/s (where appropriate)

Name:	Ruth Anna Weber
University address for correspondence:	University of Gloucestershire - England Registered number: 06023243. Registered office: The Park, Cheltenham, GL50 2RH
Telephone Number:	Click here to enter text.
Fax Number:	Click here to enter text.
University e-mail Address:	Click here to enter text.

Name:	Dr. Francisca Veale	Name:	Prof. Dr. Michael Erhart
University address for correspondence:	University of Gloucestershire  England Registered number: 06023243. Registered office: The Park, Cheltenham, GL50 2RH	University address for correspondence :	APOLLON Hochschule der Gesundheitswirtschaft GmbH Universitätsallee 18, 28359 Bremen Germany Professur für Psychologie insbesondere Klinische Psychologie und Diagnostik
Telephone Number:	Click here to enter text.	Telephone Number:	Click here to enter text.
Fax Number:	Click here to enter text.	Fax Number:	Click here to enter text.
University e-mail Address:		University e-mail Address:	



Project Title:	Towards the Quality of Care for Oncological Patients:  – an Evaluation of a New Approach to Contribute New Knowledge
Start Date:	October 2014
Completion Date:	October 2018

# Title of Study: Towards the Quality of Care for Oncological Patients: -an Evaluation of a New Approach to Contribute New Knowledge

As a researcher, I have to justify from an ethical point of view why this research is necessary and why it will produce positive and identifiable benefits for the patients (see Attachment I: Declaration and Agreement). The aim of my study is to enhance the quality of oncological care by evaluating patient satisfaction and quality of life. Patient satisfaction will be evaluated by way of a semi-structured interview and quality of life will be evaluated with a questionnaire. More specifically, this study aims to improve the quality of oncological care in an outpatient unit that is organized by a new supply structure called Ambulatory Specialized Care. I will examine to which extent the introduction of Ambulatory Specialized Care optimizes the quality of oncological care in the outpatient unit and to which extent it provides tangible benefits for patients.

It shall be demonstrated that the quality of oncological care in a single outpatient unit be evaluated, based on a qualitative determination of quality of life and patient satisfaction. Up to now, these parameters have only been recorded quantitatively in long trials with large numbers of patients. It is beneficial for patients to receive rapid results rather than filling in a number of different questionnaires over an extended time period.

My research strategy focuses specifically on the needs of patients with chronic and long-term illnesses because they require continuous, comprehensive care that is based on their personal needs and expectations. Each participant in this study will be given the opportunity to talk freely in a pleasant and quiet environment. At the patients' request, the information obtained from the interview can be passed on to the doctors that will be involved in future treatment (see Attachment III: Interview for patients after informed consent).

The study is entirely voluntary and the participants will only be included in the study if they provide written consent. Participants can refuse to answer any of the questions, and can withdraw from the study at any time without penalty or loss of privileges. All participants are subjected to the same conditions and should be treated equally (see Attachment II: Informed consent).

The literature that I have reviewed indicates that the majority of studies that have been conducted to date in this field use quantitative research methodologies when evaluating healthcare. I will be applying qualitative research methods to evaluate patients' subjective experiences. My research strategy will be based on a combination of semi-structured interviews and questionnaires. The employment of these methods will lead to greater consideration of patients' needs, perceptions and impressions of life in general while they undergo medical treatment. The results will provide a conceptual framework which could be

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#### Supporting documentation

Please ensure that when preparing applications to UREC using the UREC Research Ethics Proforma that the following are included on the form or within the project description attached to the form, where these are of relevance (this may speed up the process of approval):

- a) sample information sheet to be given to participants and sample letters about voluntary informed consent and withdrawal (beware of any possible problems of coercion), written in good clear English. University addresses should be used; (depending on timing of the UREC/FREP consideration this may be inappropriate)
- b) statement about any conflict of interest;
- statement about DBS check (Criminal Records Bureau) https://www.gov.uk/government/organisations/disclosure-and-barring-service;
- copies of questionnaires and/or interview schedules and questions, even if in early draft form (depending on timing of the UREC/FREP consideration this may be inappropriate).

UREC's/FREP's decision-making will be more straightforward if you have covered the following issues in your project description. If you need to, attach further information.

- the nature of the observation of human participants;
- the outline planning and procedures for focus group research or one-to-one interviews to include establishing ground rules affecting revelation of any personal details to the group;
- (iii) that issues of power relations are taken into consideration;
- (iv) that issues of any guilty knowledge likely to arise form the research are thought through;
- the details and number of participants (age, gender, whether a vulnerable group noting that this often depends on the specific research project, size of group);
- (vi) whether this is a double blind study;
- the justification of use of photography or video and that permission concerning these are planned for;
- (viii) that issues of physical and/or psychological and personal danger affecting either the participants or the researcher have been considered fully;
- (ix) whether interviews are to be recorded electronically or manually.

#### Risk Assessment for Research

It is a University requirement that risk assessments should be completed for all staff and student research, both within and outside the University, before work commences. The purpose of the risk assessment is to identify potential hazards, and the measures that might be needed to control them. This is to help ensure the health and safety of the Researcher and of any other person that might be affected by the work.

A <u>Risk Assessment Form</u> should be completed by the Researcher. For student work this should be in collaboration with their Academic Supervisor. The Risk Assessment Form should be attached to the Ethics Application Form. It is the responsibility of the Faculty Dean to ensure that risk assessments are conducted for all research being undertaken by their Faculty. Guidance on risk assessment is available at the end of this document, and further advice can be obtained from the Health, Safety and Environment Team who can be contacted at <u>safety@glos.ac.uk</u> or on 01242-715012.



#### Risk-based Control Plan

Risk Level	Action
Very Low	No action is required, though assessment must be recorded.
Low	No additional controls are required. Consideration may be given to a more cost-effective solution or improvement that imposes no additional cost burden. Monitoring is required to ensure that the controls are maintained.
Medium	Efforts should be made to reduce the risk, but the costs of prevention should be carefully measured and limited. Risk reduction measures should be implemented within a defined time period.  Where moderate risk is associated with extremely harmful consequences, further assessment may be necessary to establish more precisely the likelihood of harm as a basis for determining the need for improved control measures.
High	Work should not be started until the risk has been reduced. Considerable resources may have to be allocated to reduce the risk. Where the risk involves work in progress, urgent action should be taken.
Very High	Work should not be started or continued until the risk has been reduced. If it is not possible to reduce risk even with unlimited resources, work has to remain prohibited.



Risk Assessment - "Aide Memoir"		
Hazard Severity	Examples of Type of Injury	
Low	Scratch, bruise, minor cut, minor burns. Normal work possible after first aid treatment.	
Medium	Burns, severe cuts, minor fractures (fingers & toes), strains, sprains, temporarily disabling back injuries. Accident results in loss of time less than 3-day injury.	
High	Permanent disability, amputations (e.g. loss of finger) other fractures, over 3-day injury, multiple injuries, fatalities.	

Description of Likelihood	Example
Not likely	Harm will seldom occur.  So Unlikely, probability close to zero, e.g. the chance of being struck by lighting in UK.
Possible	Harm will occur frequently.
Likely	Harm is certain or near certain to occur. Occurs repeatedly, to be expected. If conditions continue an accident or incident is almost certain to occur.

Express the level of risk associated with identified hazards by multiplying the hazard severity by the **likelihood** of the hazard occurring.
Consult the risk matrix, to express the risk level:

# Risk Level

Likelihood → Hazard Severity ↓	Not Likely	Possible	Likely
Low	Very Low	Low	Medium
Medium	Low	Medium	High
High	Medium	High	Very High

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#### Risk Assessment

#### Risk Assessment for Research

It is a University requirement that risk assessments should be completed for all staff and student research, both within and outside the University, before work commences. The purpose of the risk assessment is to identify potential hazards, and the measures that might be needed to control them. This is to help ensure the health and safety of the Researcher and of any other person that might be affected by the work.

A <u>Risk Assessment Form</u> should be completed by the Researcher. For student work this should be in collaboration with their Academic Supervisor. The Risk Assessment Form should be attached to the Research Ethics Application. It is the responsibility of the Faculty Dean to ensure that risk assessments are conducted for all research being undertaken by their Faculty. This document provides guidance on risk assessment, and further advice can be obtained from the Health, Safety and Environment Team who can be contacted at <u>safety@glos.ac.uk</u> or on 01242-715012.

#### Hazard Prompt List:

During work activities could the following hazards exist?

- 1. Contact with Moving Machinery.
- 2. Slips, Trips and Falls, e.g. on the same level, from heights etc..
- 3. Struck by Objects, e.g. falling tools, ejection of material etc..
- 4. Striking against Objects, e.g. inadequate headroom, etc..
- 5. Hazards associated with Manual Handling (Cross reference with Manual Handling Assessments).
- 6. Contact with Substances (Cross-reference with COSHH Assessments)
- 7. Biological Hazards, eg rats urine
- 8. Vehicle hazards, covering both site transport and travel by road.
- 9. Harmful energies e.g. Electricity, radiation, noise, vibration
- 10.Fire and explosion
- 11. Lone Working
- 12.Violence
- 13.Pregnant Workers
- 14. First Aid provision



# Before submitting your application to FREP/UREC please check and complete the following check

Checklist	
Have you completed all sections of the ethics approval form?	Yes
Have you completed a risk assessment (and noted risk to participants AND researchers?)	Yes
Have you included recruitment materials (e.g., posters, email pro forma, flyers)	No
Have you included your information letter (s) – this includes letters to parents, participants and organisations	Yes
Have you included your consent form (s) – includes consent to parents and/or assent to participants if they can make an informed judgement about whether they want to participate (even if under 18 years)	No
Have you enclosed a copy of your CRB (if appropriate)	No
Have you enclosed a copy of interview questions / questionnaires (if appropriate)?	Yes
Have you included information regarding how long you will keep data, where it will be stored, and how you will destroy data	Yes
Have you indicated measures that will be taken to protect and maintain the anonymity and/or confidentiality of participants	Yes
Have you enclosed any other supporting material (please specify)	No



# RISK ASSESSMENT RECORD SHEET (see pages 10-12 for more information):

Assessed by: Click here to enter text.

Possible Hazards	Severity (without control measures)	Persons exposed (employees, students etc	Risk Control Measures Currently in place	Likelihood (with control measures)	Risk Level	Action Required	Action Completed (date and signature)
	Choose an item.			Choose an item.	Choose an item.		Click here to enter a date.
	Choose an item.			Choose an item.	Choose an item.		Click here to enter a date.
	Choose an item.			Choose an item.	Choose an item.		Click here to enter a date.
2	Choose an item.			Choose an item.	Choose an item.		Click here to enter a date.
	Choose an item.			Choose an item.	Choose an item.		Click here to enter a date.
	Choose an item.			Choose an item.	Choose an item.		Click here to enter a date.
	Choose an item.			Choose an item.	Choose an item.		Click here to enter a date.

Hazard: Something that has the potential to cause harm

Severity: The degree of harm which the uncontrolled hazard has the potential to cause

Likelihood: The probability that the hazard potential will be realised, taking into account any risk control measures in

place
Risk:Risk expresses the likelihood that the harm from a particular hazard is realised, taking into account Severity.

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Dear Ruth,

Thank you for the further information you sent in response to our useful and informative discussion about your project. I am sorry that it has taken a while to get back to you.

I am delighted to report that I have had the opportunity to review the documents, and confirm that these meet our requirements, and that the project is therefore approved.

The reference number is REC.16.37.4

Do you need a letter other than this email message confirming ethics approval? If so, I can provide one.

Best wishes

Dr. Malcolm MacLean Chair, Research Ethics Committee

Dr. Malcolm MacLean Reader in the Culture and History of Sport, Exercise & Sport Research Centre University of Gloucestershire
Oxstalls Lane
Gloucester GL2 9HW
England



- 1. Enclosed as per your request is a copy of the informed consent in German.
- 2. Information about the German legal environment:
  - Research projects in Germany only need to pass an ethical vote in clinical trials of medical products and drug application. Standardized questionnaires and interviews need no ethical declaration if the vote is
  - within a quality management project as a research goal. The research aim in my case is to improve the effectiveness of quality management in an outpatient unit organization.
- To satisfy the English ethical requirements I obtained the permission of the medical director of the outpatient unit.
- 4. To clarify the part of the informed consent that mentioned "loss of privileges": This term was a result of an erroneous translation from German into English. The German version as you can see is without this term. I have now removed this term in the English version.
- 5. With regard to the patient data confidentiality:
  - a) Patient data will only be shared with the treating doctor in case of an explicit wish of the patient.
  - b) The medical treating doctor is legally obliged under the Hippocratic oath to maintain patient confidentiality.
- 6. With regard to the possibility of patients perceiving questions as intrusive: Please see the attached risk assessment record sheet. In the case that patients feel intruded upon they can stop or interrupt the interview.
  I will guarantee that deep personal conflicts will not be discussed in the study.
- The interviews take place in a private room in our practice. This is a relaxed and protected atmosphere. Normally we used this room for events and celebrations. The room will be available without any limitations.

I have thought a lot about what you wrote in the email and what we have discussed. I am taking this ethical review very seriously and have taken into consideration all possible hazards.

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# Risk assessment (see pages 10-12 for more information)

Risk assessment			
Faculty/Department:	Click here to enter text.		
Campus	Choose an item.	Click here to enter text.	
Location:	Choose an item.	Click here to enter text.	
Assessment Date: Manager/HoD/Dissertation Supervisor Signature:			
	The reference number	at the project is therefore approved. er is REC.16.37.4 n Chair, Research Ethics Committee	
Date	25. October 2016		
	Click here to enter a date.		

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If this project requires the use of any special procedures or techniques, please describe any training or competency assessment to be undertaken by investigator(s).

As a researcher I have received training in qualitative interview and data analysis provided from my research supervisors.

#### Anonymity / Confidentiality

Please indicate measures that will be taken to protect and maintain the anonymity and/or confidentiality of participants.

In my research I guarantee all participants confidentiality and do not pressure patients to get information. I have to respect the current regulations of data protection. I will keep all data private and secret in a looked office and only the researcher and treated doctor will have access to the data. I will keep data for five years after the study has finished. All data will be destroyed after five years the latest. The participants are reminded, that I will present the results at conferences and publish the results in an academic journal. No participant will be identifiable by name, I will code all patients features with consecutive ident-numbering.

Data storage		
Where will your data be stored?	In a closed office room with lockable doors I will keep all gathered da on a password-protected computer and additional copied on a USB Sti for saving all data in case of a risk assessment.	
Will data be stored in secure premises (e.g., locked lab or office, password protected computer)	Looked office, password protected computer.	Click here to enter text.

Signature of researcher(s)	)	
	Ruth Anna Weber	40
		Click here to enter a date.
		Click here to enter a date.
Signature of supervisor (s) (if appropriate)		Tuesday, 19 July 2016
	Dr. Francisca Veale	
		Click here to enter a date.
		Wednesday, 20 July 2016
	Prof. Dr. Michael Erhart	

NB: forms not fully completed and signed by researcher/s and supervisor/s (where appropriate) will be returned.

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researcher, when appropriate, will stop the interview.

5. In my research, I will guarantee the confidentiality of all participants and will not pressure patients into providing information.

Risk of Harm		
<ul> <li>Please indicate any possible <u>risks</u> to the <u>researchers</u>, <u>participants</u>, <u>other persons or the environment</u>: (Please tick as appropriate)</li> </ul>		
1. Environmental	Choose an item. Not applicable	Click here to enter text.
2. Legal	Choose an item. Not applicable	Click here to enter text.
3. Physical	Choose an item. Not applicable	Click here to enter text.
4. Physiological	Choose an item. Not applicable	Click here to enter text.
5. Psychological	Semi- structured interviews and standardized questionnaires	Click here to enter text.
6. Social, Cultural and Professional	Choose an item.	Click here to enter text.

 If you have ticked any of the previous remarks, please describe the actions that will be taken to minimise the risk.

In the attachment the interview questions and questionnaire document can be found. The interview questions were created with consultation from my research supervisor. He is experienced as a Professor of psychology in this area. I do not believe that these questions are psychologically intrusive. In order to identify and assess possible risks and complications, I do so before I begin my project. Therefore, I will setting up a continuous risk management so as to minimize project risks and providing answers to solution-critical questions. In case of patients' severely illness and treatment environment and the consequences of which are as yet incalculable might well enhance some participants fears and heighten the sense of strangeness and hence the fear and insecurity felt by those seeking treatment. As a result of the interviews a confrontation with the case of illness really cannot be avoided. On the one hand, in a range of situations in patients' everyday life in communication in their social environment that issues will arise regarding their cancer disease. In contrast, a possible confrontation conducting the interview can occur but under certain controlled conditions. If the disease situation requires it, patients knowing that in case of conflict they can quickly make an appointment for a personal meeting with the attending physician.



Volu	Voluntary Informed Consent				
a)	Please indicate what form of consent will be used in this investigation	Written			
b)	How and by whom will the voluntary informed consent particular if participants/respondents/subjects are child 'vulnerable populations'. (Letters to participants and/o form.) see Attachment I,II,III	Iren or young people, or are members of other			

My comparative case study research includes asking questions with a special group of severely ill cancer patients. The study will not knowingly include children but other vulnerable groups. I do not intrude upon the privacy of the vulnerable participants. The research based on the freely given informed consent and obtained no covert methods. The participants get fully informed about the aims, duration and possible consequences of the research. The researcher guaranteed that the participants not pressured into participation and have the right to refuse participation at any time and any stage of the research project. The participants can exit the research study at any time without reasons. The participants are able to sign the informed consent. The letter of information and the informed consent document can be found in the attachments.

#### Reposits and rick

What are the benefits of the proposed research to the participants and/or for scientific knowledge in general?

The aim of my study is to examine patients' satisfaction and their quality of life, for the application to enhance the quality of oncological care. To evaluate this research, with the aim of continuously improvement of the quality of oncological care in an outpatient unit undergoing a new supply structure - the ambulatory specialized care. Furthermore, to which extend the introduction of a new supply structure will optimizing the quality of oncological care and leads to a beneficial improvement for the patients. My research strategy focuses on the benefit for the patients care because chronic and longterm-ill patients need continuing comprehensive care based on their personal needs and expectations. Each participant in this study will be given the opportunity to talk freely in a pleasant and quiet environment. At the patients' request, the information obtained from the interview can be passed on to the doctors that will be involved in future treatment (see Attachment III: Interview for patients after informed consent).

What are the adverse effects may result from the research? How will these adverse effects be dealt with?

I will set up a continuous risk management plan so as to minimize project risks and provide answers to critical question.

- The researcher will improve the informed consent form and clarify the questions in general. After personal time for consideration, participants can give their approval to the researcher.
- The treating doctor will use both interviews and questionnaires to obtain valid and detailed information.
- Interposed questions during the interview by the researcher that the participant will be able to carry out the further survey.
- 4. Statements or indications made by patients which reveal deep, personal conflicts will not be discussed in the study, as there is no direct relationship between these personal conflicts and the aims of the study. The

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		finished the research at the latest. The research based on the freely given informed consent and obtained no covert methods. The participants get fully informed about the aims, duration and possible consequences of the research. The researcher guaranteed that the participants not pressured into participation and have the right to refuse participation at any time and any stage of the research project. I respect all 8 items of the data protection principles of the (DPA 1998 UK).
8 Has another form of 'risk assessment' been undertaken (in addition to this form)?	Yes	In a looked office room I will keep all gathered data on a password-protected computer and additional copied on a USB Stick for saving all data in case of a risk assessment.  All participants have the option of rejecting the use of gathered data and of digital devices such as tape-recorders or cameras.



			Click here to enter a date.
3	Will the participants/respondents/ subjects include children and/or young people and/or members of other vulnerable populations?	Yes	Brief details:  Participants will be a special vulnerable group of severely ill cancer patients. This study requires sensitivity from the part of the researcher, the informed consent of all participants and the assurance that the privacy of the participants will be protected. The participants can exit the research study at any time without reasons.
4	Are participants at risk of experiencing psychological, social or physical harm or discomfort? (If yes, see sections on 'risk of harm' and 'voluntary informed consent' below)	No	Brief details: In my research, all patients will be granted anonymity, and I will ensure they come not to harm or under pressure, there is no risk for the researcher and the participants.
5	Have any training needs been identified for the researcher(s)?	Yes	Brief details: The researcher has participated in Ethics and Good Clinical Practices Guidelines. The researcher followed the WHO according to the Helsinki Declaration.
6	Have relevant professional guidelines been consulted?	Yes	Source of guidelines: Ethical guidelines provided by the GCP criteria (Good & Good, 1981). University of Gloucestershire Ethics Handbook of Principles and Procedures, (URDC, 2008) App. 5
7	Have actions been taken to ensure compliance with the Data Protection Act 1998 (DPA)	Yes	Actions taken to protect all personal data. All participants have the option of rejecting the use of gathered data and of digital devices such as tape-recorders or cameras. All records will be destroyed at the end of the process, 5 year after having

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utilized to enhance professionals' approaches in the care of oncological patients.

In my research, I must be able to estimate whether my findings will have ethically relevant positive or negative consequences for the participants. I will strive to identify and assess possible risks and complications before I begin my project. I will set up a continuous risk management plan so as to minimize project risks and provide answers to critical questions. Factors such as the treatment environment and the severity of patient illnesses may enhance the fear and insecurity experienced by some participants.

As a result of the interviews a confrontation with the case of illness really cannot be avoided. On the one hand, in a range of situations in patients 'every day life in communication in their social environment that issues will arise regarding their cancer disease. In contrast, a possible confrontation conducting the interview can occur but under certain controlled conditions. If the disease situation requires it, patients knowing that in case of conflict they can quickly make an appointment for a personal meeting with the attending physician.

Risk management: The following steps will be taken to prevent such situations:

I will improve the informed consent form and clarify the questions in general. After personal time for consideration, participants can give their approval to me.

The treating doctor will use both interviews and questionnaires to obtain valid and detailed information in case of deterioration of the participant.

Interposed questions during the interview by the researcher that the participant will be able to carry out the further survey.

Statements or indications made by patients which reveal deep, personal conflicts will not be discussed in the study, as there is no direct relationship between these personal conflicts and the aims of the study. The researcher, when appropriate, will stop the interview.

In my research, I will guarantee the confidentiality of all participants and will not pressure patients into providing information.

I have to respect the current regulations of data protection. I will keep all data private in a locked office and only the researcher and treated doctor (at the patient's request) will have access to the data. I will keep the data for five years after the study has been finished. All data will be destroyed after five years the latest. The participants are reminded that I will present the results at conferences and publish the results in an academic journal. No participant will be identifiable by name and I will code all patients features with consecutive ident-numbering.

### Is there any element of this proposal that makes reference to UREC/FREP mandatory?

Yes

#### If yes, please indicate which

My comparative case study research includes asking questions with a special group of severely ill patients. The study will not knowingly include children but other vulnerable groups.

About the proposed project			
1	Is partnership /collaboration with another institution involved?	No	Name of institution: Click here to enter text.
2	Has another Ethics Committee scrutinised the project?	No	Ethics Committee & date of scrutiny:

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# 11 Appendix C: Methods

### TABLE 58: INTERVIEW GUIDE GERMAN - ENGLISH

### Interviewfragebogen: Interview guide

#### Global

- a) Wie geht es Ihnen heute. <u>Ihr allg. Befinden?</u>
  How do you feel today? What <u>do you expect of your treatment at this medical practice?</u>
- b) Welche Hoffnungen verbinden Sie mit der Behandlung in unserer Praxis? What outcome(s) do you hope will result from the completion of your treatment at this medical practice?
- c) Was fällt ihnen als erstes ein, wenn Sie an ihre Sorgen und Ängste in ihrer <u>jetzigen Situation</u> <u>denken?</u> What are your main concerns and fears relating to your situation?

#### I Internal aspects

- d) Glauben Sie <u>ausreichend</u> über ihre Erkrankung und Behandlung <u>informiert</u> zu sein? Do you think you would be <u>sufficiently well-informed</u> about your disease and treatment options?
- e) Wie haben Sie die <u>Vermittlung Ihrer Diagnose</u> in unserer Praxis erlebt?
   How well did we <u>explain</u> your diagnosis? How did you <u>feel</u> when given your diagnosis?
- f) Wie beurteilen Sie die Möglichkeit mit dem Arzt zu sprechen? How easy is it to speak with your doctor in a relaxed atmosphere?
- g) Haben Sie den Eindruck, dass ihr Arzt Ihnen <u>ausreichend zuhört</u> und sie dabei <u>ernst nimmt?</u>
  Do you feel that your doctor <u>listens attentively</u> to your problems and takes them <u>seriously?</u>

#### II Patient education and information

- h) Wie gut haben Sie die Erklärung über verschiedene Behandlungsmöglichkeiten Ihrer Erkrankung erlebt? How well have you <u>understood</u> the various treatment options available to you and the severity of your illness?
- i) In wie weit wurden Sie in die Entscheidung und Durchführung Ihrer Therapie mit einbezogen? How much have you been included in the decision-making process and realisation of the therapy?
- j) In wie weit glauben Sie über die Nebenwirkungen Ihrer Therapie <u>ausreichen informiert</u> zu sein? Do you feel that you have been <u>sufficiently informed</u> about the possible side effects of your therapy?
- k) In wie w

  ürden Sie sich mehr psychologische Unterst

  ützung w

  ünschen? To what extent do you require additional psychological support?

### III Accessibility of care and treatment environment

I) Wie beurteilen Sie die Kooperation (Informationsaustausch mit anderen Ärzten und fachlicher Austausch) mit den externen medizinischen Einrichtungen im Zusammenhang mit Ihrer Tumorerkrankung? How well do you feel that the doctors treating your cancer disease reach out to other medical institutions on you teshalt?

#### (cooperation and business exchange)

- m) Wie beurteilen Sie die Koordination, Termine, Wartezeiten mit den externen und mit unserer medizinischen Einrichtung im Zusammenhang mit Ihrer Tumorerkrankung (Koordination und Termine)? How did you find the scheduling, especially the ease of making appointments when you needed them and the waiting time at external medical institutions? (coordination of appointments)
- n) Wie <u>belastend</u> finden Sie die Fahrten zur ihren Sprechstundenterminen in Zusammenhang mit Ihrer Tumorerkrankung? How <u>burdensome and stressful</u> are the traveling distance to chemotherapy and consultation hours associated with your cancer?
- o) W: In wie weit w
  ürden Sie Ihren Familienangeh
  örigen und Freunden unsere Einrichtung weiterempfehlen, falls diese eine b
  ösartige Erkrankung erleiden sollten? Would you recommend our medical practice to friends and relatives if they suffered from cancer?

## FIGURE 12: QUESTIONNAIRE SF-12 WITH ITEMS AND SUBSCALES

This survey asks for your views abo well you are able to do your usual a unsure how to answer a question, p	ctivities. Answer	each questio	n by choos			
1. In general, would you say your	health is:					
□ Excellent □ Very good	□ Good	□₄ Fair	C	□ Poor		-
The following questions are about the following questions are about the following the		might do duri	ng a typical	day. Does y	our health now	
mint you in these activities? If so	, now mach?	YES, limited a lot	1	YES, imited	NO, not limited at all	
<ol> <li>Moderate activities such as moving a vacuum cleaner, bowling, or pl</li> </ol>		П	- 77	□2	□2	
Climbing several flights of stairs		Dr.		32	D <sub>1</sub>	
<ol> <li>Accomplished less than you was.</li> <li>Were limited in the kind of work During the past 4 weeks, have yo</li> </ol>	or other activitie		Di Di oblems with	your work o		_
daily activities as a result of any	emotional proble	ems (such as	feeling dep	ressed or an	xious)?	
daily activities <u>as a result of any</u>	emotional probl	ems (such as	feeling dep YES	ressed or an	xious)? NO	
		e <u>ms</u> (such as	COMPANIAN .	ressed or an	D-244440	
Accomplished less than you w     Did work or activities less careful	ould like. ully than usual.		YES		NO	de
6. Accomplished less than you w. 7. Did work or activities less careful. 8. During the past 4 weeks, how the home and housework)?  1. Not at all 2. A little bit These questions are about how y. For each question, please give the	ould like.  ully than usual.  much did pain in  Modo  ou have been fee one answer the	nterfere with y erately eeling during t	YES  our normal  Quite a	I work (includ a bit veeks.	NO  D2  D3  ding work outsid	de
5. Accomplished less than you w. 7. Did work or activities less careful. 8. During the past 4 weeks, how the home and housework)?   Not at all	ould like.  ully than usual.  much did pain in  Modo  ou have been fee one answer the	nterfere with y erately eeling during t	YES  our normal  Quite a	I work (includ a bit veeks.	NO  D2  D3  ding work outsid	Non of th
5. Accomplished less than you w 7. Did work or activities less carefe 8. During the past 4 weeks, how the home and housework)?  1. Not at all  2. A little bit 1. These questions are about how y for each question, please give the how much of the time during the	ould like.  ully than usual.  much did pain in  usual.  Modiou have been fee one answer the  past 4 weeks  All of the	erately seling during to at comes close  Most of the	YES	a bit veeks. way you have Some of the	NO  Da  ding work outsid  Extremely  been feeling.  A little of the	Non of th
5. Accomplished less than you w 7. Did work or activities less careful 8. During the past 4 weeks, how the home and housework)?  1. Not at all	ould like.  ully than usual.  much did pain in  usual.  Modiou have been fee one answer the  past 4 weeks  All of the time	erately seling during to at comes close Most of the time	YES	a bit veeks. way you have of the time	NO  Da  ding work outsid  Extremely  been feeling.  A little of the time	Non of th time
6. Accomplished less than you w 7. Did work or activities less careft 8. During the past 4 weeks, how the home and housework)?  1. Not at all 2. A little bit These questions are about how y For each question, please give th How much of the time during the 9. Have you felt calm & peaceful? 10. Did you have a lot of energy? 11. Have you felt down-hearted and blue?	ould like.  ully than usual.  much did pain in  under head ou have been fee one answer the  past 4 weeks  All of the time  under head output for the time  under head output for the time  under head output for the time	erately seling during that comes close Most of the time	YES	s bit  yeeks.  Some of the time	NO  Da  ding work outsid  Extremely  been feeling.  A little of the time  Da	None of the time

TABLE 59: COMPARISON OF SEMI STRUCTURED INTERVIEW AND QUESTIONNAIRE

	Advantage	Disadvantage
Semi-structured Interview	<ul> <li>Sensitivity for clinical relevance and changes</li> <li>Focus of interested topic area</li> <li>Identifying factors of importance</li> <li>Personal contact</li> <li>Yielding more detailed account of patients' perceptions</li> <li>High response rate</li> </ul>	<ul> <li>Interviewer bias possible</li> <li>(to give socially acceptable responses)</li> <li>Lack of anonymity</li> <li>Time consuming labour intensive=costly</li> <li>Even for small samples, which may not be representative</li> </ul>
Questionnaire	<ul> <li>Disease specific and health related</li> <li>Only relevance standardized questions will be asked (economy)</li> <li>High validity and reliability</li> <li>Large collection of data</li> <li>Economical and easy to administer</li> </ul>	<ul> <li>Not comprehensive</li> <li>A proper comparison between different diseases and living conditions is not possible</li> <li>Burdensome because of lot of items and inappropriately worded questions</li> <li>Not patient-orientated</li> <li>No in-depth approach</li> </ul>

FIGURE 13: TRANSCRIPTION PROCESS

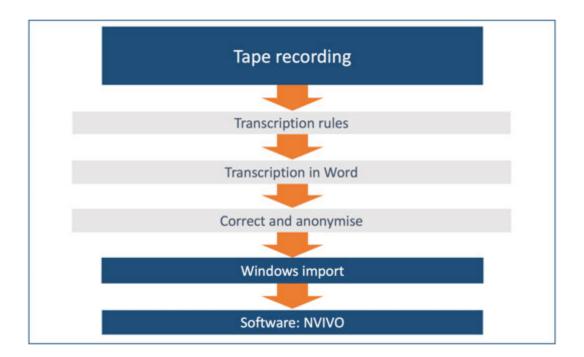


Table 14: Example of initial category building

Five Steps	Examples	Constructed Code	Code #
Definition as clearly as possible of themes for the categories	e.g. category of subjective meaning and expectation of treatment at this medical practice	Assistance and support by the physician	2
		Adequate treatment Alternative	12
		treatment Information about	13
		treatment Coordination	18
		Transparency and information	22 27
Approach determined in detail	Line by line analysis of interview text. If the content fits to the below mentioned question the text will be assigned to the category		
Building new categories	Relevant text passages build a category e.g.	What are your main concerns relating to your treatment?	3
Assumption of existing categories	Decision making of each interview text existing category or building a new one.	Interpersonal: Appreciation- assistance and support Trust in the doctor	1 2 7
Building main- and sub- categories	Set of categories will be structured in straight line order and three main categories remain	Close to practice: ad1. Interpersonal ad2. medical ad3. organisational	Ad1: 1-9 ad 2: 10-19 ad3: 20-29

TABLE 15: POSITIVE AND NEGATIVE QUALITY OF LIFE ATTRIBUTES (A)

Positive and negative quality of life attributes	Table A): physical well-being
Positive attributes:	Negative attributes:
General medical and physical - functioning	Disease and treatment specific - disfunctioning
Acceptance	Being a burden, stressful
Adequate or alternative treatment	Feeling dependent
Cooperation	Can take care of myself
Enough time	Can do things on my own
Fighting against cancer – expected outcome	Having normal life, normal functioning
Information about diagnosis and treatment	Absence of information,
Patient activation for ongoing procedures shared-decision-making	Be at the mercy's of doctor, staff and other medical institutions

TABLE 16: POSITIVE AND NEGATIVE QUALITY OF LIFE ATTRIBUTES (B)

Positive and negative quality of life attributes	Table B) supportive and organizational well-being
Positive attributes:	Negative attributes:
Supportive and organizational relation	No supportive accomplishments
Appointments	Not enough time, lack of time, stressful
Quality of service	Lack of quality of service
Willingness to recommend the organization	Unwillingness for recommendation
Waiting times and travel distance	Too far, too long, to burdensome
Continuity of support	Service not accessible, treatment interruptions, low level of continuity
Personal stress	Feeling unsuccessful to achieve goals
Transparency and information	Cannot follow, need for more clarity

TABLE 17: POSITIVE AND NEGATIVE QUALITY OF LIFE ATTRIBUTES (C)

Positive and negative quality of life attributes	Table C) interpersonal and psychological well-being
Positive attributes:	Negative attributes:
Psychological and social relations:	Coping and non-social relations:
Assistance and support by the physician	Lack of support
Норе	Unhappy, arguing with family
Concerns, worries	Loneliness
Trust in the doctor	Lack of confidence and trust
Well-being and satisfaction	Selfish and not understanding others
Appreciation doctor-staff	Not providing value
Integration personal needs	Feeling uncomfortable

TABLE 60: NODE REFERENCING POINTS – MAIN NODES AND SUBNODES. MEANINGS AND DESCRIPTION (CATEGORY I)

Sub nodes	I. Interpersonal – Main node (not medical not organisational)	Short description – Importance of the concept
1.	Appreciation doctor-staff: Evaluation of relationship between patient and doctor	Interpersonal matters between patient-doctor-staff. The patient appreciates the interpersonal relationship; he or she wishes for more or there is a professional sense of trust between doctor and patient.
2.	Assistance and support by the physician and team members	Patient wishes for support or expresses the wish for greater support and assistance.
3.	Concerns Requests, matter, issues	Patient expresses or raises concerns regarding the physician or team.
4.	Consolation Encouragement, emotional assistance	Patient has received consolation and encouragement from doctor that is not medical.
5.	Hope Hope	Patient expresses hope interpersonally.
6.	Integration and personal needs  Personal expectations, communication between doctor and patient.	Inclusion and involvement in decision making and in the treatment process, interpersonally.
7.	Trust in the doctor  Trust in the doctor interpersonal	Trust in the work and doctor's ability.
8.	Well-being Sense of well-being and satisfaction	Patient expresses well-being and satisfaction with the support of team-doctor-patient.
9.	Worries Sorrows, fears	Patient expresses his sorrows and fears in relation to his social and financial situation.

TABLE 61: NODE REFERENCING POINTS — MAIN NODES AND SUBNODES. MEANINGS AND DESCRIPTION (CATEGORY II)

Sub		
nodes	II. Medical – Main node	Short description –
		importance of the concept
	(not interpersonal not organisational)	
	Acceptance	Acceptance of medical diagnosis
10.	Improvement, acceptance, apprecia-	
	tion in medical relation	
	Accessibility	Patient satisfaction with accessibil-
11.	Availability and responsibility	ity and responsibility from doctor
		and staff.
	Appropriate treatment	Medically adequate treatment and
12.	Appropriate treatment and communi-	patient-doctor communication.
	cation	
	Alternative treatment	Patient addressed this topic. Dis-
13.	Information about alternatives in rela-	cussion between patient and doc-
	tion to treatment and disease	tor about other treatment options.
	Cooperation	Doctor works with colleagues and
14.	Lively discussion and exchange	other medical institutions. Patient
14.		desires a lively doctor-doctor dis-
		cussion (in conferences).
	Enough time	Patient expresses that he or she has
15.	Sufficient time	enough time; doctor-patient-con-
		versation.
	Fighting against cancer	Patient express that he or she is
16.	Fighting against his disease	willing to fight against the cancer
10.		during his treatment, and to use all
		options.
	Information about diagnosis	Patient is sufficiently well informed
17.	Sufficient and appropriate information	about his diagnosis, he/she desires
	about his diagnosis	more or less information.
	Information about treatment	Patient is sufficient and well in-
18.	Sufficient and appropriate information	formed about his treatment,
10.	about his treatment	he/she wishes more or less infor-
		mation.
	Patient activation	Taking into account that patient
	Further involvement and activation in	wishes for more doctor-patient
19.	treatment side-effects- ongoing proce-	communication in treatment pro-
	dures.	cesses as well as shared decision
		making, finally expected outcome.

TABLE 62: NODE REFERENCING POINTS — MAIN NODES AND SUBNODES. MEANINGS AND DESCRIPTION (CATEGORY III)

Sub nodes	III. Organisational – Main node (not interpersonal not medical)	Short description – Importance of the concept
20.	Organisational appointments Appointments, dates and meetings.	Good appointment-making procedure
21.	Continuity of support  Continuity of treatment, accessibility and service.	In this context organisationally to- wards appointments and further treatment, no treatment interrup- tions, persistent high level of conti- nuity.
22.	Coordination  Consultation and coordination.	Organisationally patient wishes to have coordination, communication and consultation of his appointments with doctor-patient or doctor-doctor.
23.	Personal stress  Pressure and burden, tension related on the organisational situation of the patient.	Possible burden and other charges in organisation between doctorpatient.
24.	Quality of service Scope of service, high quality of service.	ity of service towards the patient, he/she evaluated the organisation towards the quality.
25.	Recommend the organisation  Personal referral and recommendation  of the patient	Patient recommends the practice.
26.	Rush  Lack of time, to much stress and hectic.	Patient evaluates and express in relation to doctor/staff and himself that he/she or the organisation is to stressful, the organisation of waiting-times and appointments is lack of time.
27.	Transparency and information Transparency and disclosure	All appointments, upcoming examinations and procedures in organisational relation.
28.	Waiting times and travel distance	Organisationally patient wishes and his expressions about appointments and waiting-times and burden of these processes.

	Far from practice financial,	Patient express a burdensome fi-
29.	financial issues	nancial situation has nothing to do
		with the surgery or his treatment.
	Far from practice personal conflicts	Pre-existing conflicts which patient
30.	Personal conflicts pre-existing, nothing	have experienced beforehand. In
30.	to do with the current situation in this	relation to hospital or other doc-
	surgery.	tors.
	Far from practice social	Answers during the interview with-
	Social aspects family and beloved once	out a context or no position to the
31.	related. Not this surgery related, not	questions. Related to family and
	organisational or medical towards the	other social contacts.
	current situation.	

FIGURE 14: PROCESS DESCRIPTION OF A QUALITATIVE CONTENT ANALYSIS (OWN SOURCE)

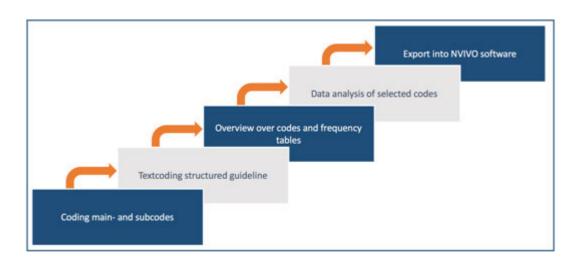


FIGURE 15: DEVELOPMENT OF A CODE FLOW CHART (OWN SOURCE)

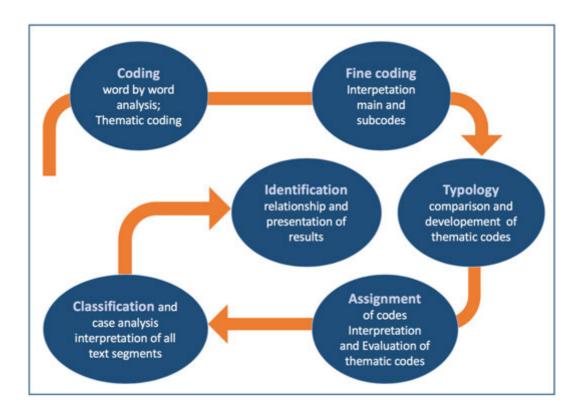


FIGURE 9: Conceptual framework (own source)

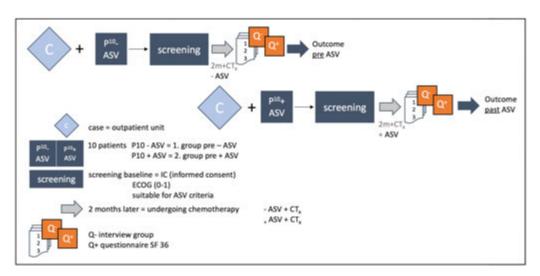


TABLE 63: SEMI-STRUCTURED INTERVIEW GUIDE (1)

Category/ Item	Research Objective
1 Introduction	
Explaining the background of the pre- sent research project	To provide definitions for quality of life and patient satisfaction
<ul> <li>Explaining the approximate required interview duration – 25 -30 minutes</li> </ul>	To record patient perceptions of quali- ty of life and satisfaction
<ul> <li>Explaining information on consent form, especially:</li> <li>participation is free and voluntary</li> <li>at any time the interview can be stopped</li> <li>confidentially is guaranteed and no traceability is possible</li> <li>the interview will be audio-taped and later transcribed</li> <li>the transcript will remain anonymous</li> <li>The results of this interview will be published as part of the thesis</li> </ul>	Compliance with the ethical standards of scientific research and the Handbook of ethical approval of the University of Gloucestershire
Ready to be signed for consent to con- duct the interview	Approval for conducting the interview
Explaining what the aim of the doctoral research is.	<ul> <li>To identify, by way of semi-structured interview, quality of care in patient perceptions of satisfaction and quality of life</li> </ul>

TABLE 64: SEMI-STRUCTURED INTERVIEW GUIDE (2)

	2 Opening questions		Code
a)	What do you expect of your treatment at this medical practice?	Evaluate general patient condition and determine if the participant is able to answer / will have sufficient time to answer interview questions. Also, to evaluate trust and appreciation in the work and doctors' competence, hope, assistance and support by the physician. Doctor's work	1, 2, 7,
b)	What outcomes do you hope will result from the completion of your treatment at this medical practice?	Additional question to further reflect on the patients' outcome aspects like hope. This question provides information about the patient's acceptance of his or her medical diagnosis as well as clues about personal expectations and needs	5, 6,
c)	What are your main concerns and fears relating to your treatment?	Additional question to further reflect about fears, worries and concerns related to the treatment.	

# TABLE 65: SEMI-STRUCTURED INTERVIEW GUIDE (3)

3 Specific questions		
l Internal aspects (outcome indicators)		
The following questions are focused on the multi-dimensional aspects of Donabedian's structure-process-outcome quality processes	Basis for the following question sequence. If necessary, prompts should be applied. Participants should have enough time to reflect on the questions.	
d) Do you think you are <u>sufficiently</u> well-informed about your disease and treatment options?	Participants addressed this topic with: adequate/ or alternative treatment and communication (patient-doctor).  Participant is sufficient and well informed about his treatment – information about treatment.  Patient activation – further involvement and activation in treatment side-effects and ongoing procedures.  Integration and personal needs, expectations for decision-making and for the treatment process, acceptance, interpersonally	10, 12, 13, 18, 19
e) How well did we <u>explain</u> your <u>diagnosis</u> ? How did you <u>feel</u> when given your diagnosis?	Participant is sufficient and well in- formed about his diagnosis. Patient express hope interpersonally and consolation * maine node interper- sonal (empathy and encouragement)	4, 16,17
f) How easy is it to speak with your doctor in a relaxed atmosphere?	Assistance and support by the physician and team members. Enough time for doctor-patient-conversation. Participant is satisfied with accessibility and responsibility from doctor/staff.	11, 15,
g) Do you feel that your doctor listens attentively to your problems and takes them seriously?	Participant express his sorrows and fears in relation to his social and financial situation.  Trust in the work and doctors' competences. Concerns towards the physician or team.	3, 7, 8,

# TABLE 66: SEMI-STRUCTURED INTERVIEW GUIDE (4)

_			
h)	How well have you <u>understood</u> the various treatment options available to you and the severity of your illness?	Information about treatment and diagnosis.	17,18
i)	How much have you been included in the decision-making process and realisation of the therapy?	Integration and personal needs also patient activation for further involvement and activation in treatment and side-effects	6, 16, 18,
j)	Do you feel that you have been sufficiently informed about the possible side effects of your therapy?	Patient activation and information about treatment, trust in the work and competences of doctor	2, 3, 7, 8,
k)	To what extent do you require additional psychological support?	Worries and concerns. The participant is satisfied with the accessibility and responsibility from doctor and team.	2, 3, 9, 11,

# TABLE 67: SEMI-STRUCTURED INTERVIEW GUIDE (5)

e and treatment en- tural indicators)		
o you feel that the ting your cancer dis- out to other medical on your behalf? d business exchange)	Cooperation, continuity of support, communication and consultation of appointments between doctor- patient. Quality of service and patient recommend the surgery.	14 20 21 24 25
i find the scheduling, e ease of making ap- when you needed e waiting time at ex- cal institutions? (co- appointments)	Waiting times and travel distance, organizational appointments. Continuity of support.	17 20 21 22 28
aveling distance to by and consultation ated with your cancer	Waiting times and travel distance, trans- parency and information, personal stress	20 22 23 27
ecommend our med- to friends and rela- suffered from can-	Recommend the organisation, doctor and team	1, 7, 15 21 24 25
phic items		
to practice of employment view ender ID number		
	o you feel that the ting your cancer disput to other medical on your behalf? d business exchange)  of find the scheduling, e ease of making apwhen you needed e waiting time at excal institutions? (co-fappointments)  on some and stressful aveling distance to by and consultation atted with your cancer decommend our medicular friends and relactions are from cancer to friends and relactions are from cancer to practice of employment.	Cooperation, continuity of support, communication and consultation of appointments between doctor- patient. Quality of service and patient recommend the surgery.  If find the scheduling, e ease of making apwhen you needed e waiting time at excal institutions? (co-iappointments)  Insome and stressful aveiling distance to by and consultation ated with your cancer  Waiting times and travel distance, organizational appointments. Continuity of support.  Waiting times and travel distance, organizational appointments. Continuity of support.  Waiting times and travel distance, transparency and information, personal stress parency and information, personal stress parency and information, doctor and team suffered from can-information.

## TABLE 68: QUESTIONNAIRE WITH OWN COMMENTS

Stand	lardised questionnaire for the state of health SF-12	
to se	questionnaire focuses on the views about your health. This e how you are feeling and how you cope with your illness in the best answer you can to each question by choosing one a	everyday life. Please
Item	Subscale	Summary Scale
1.	How would you describe your general state of health?  Physical functioning  ☐ Excellent ☐ Very Good ☐ Good ☐ Fair ☐ Poor	Physical functioning: 4P 0=bad-4=excellent Normal functional ability, symptom- free
2.	Compared with the previous year: How would you describe your general state of health? Physical functioning  Lack Excellent Lack Every Good Lac	Physical functioning: 4P  0=bad-4=excellent  Physical well-being, health  Psychological functioning:  Positive mental attitude, satisfaction with life, inner peace
3.	Your day-to-day activities: On a usual day are you restricted because of your state of health? How much? Physical functioning  Yes,   Yes,   Imited a lot   Imited at all    Moderate activities such as moving a table, pushing a vacuum cleaner, bowling or playing golf.  Climbing several flights of stairs   1   1   2   1   3	Physical function- ing: 20 P Work, good food, eating, sleep, strength, normal functional ability
4.	Regarding your state of health during the last four weeks: Have you experienced any difficulties at work or while performing profession-related activities? Have you experienced any difficulties at home?  Physical functioning  Accomplished less than you would like.  Did work or activities less carefully than usual.  Did work or activities not as usual 1 1 2	Physical functioning: 4P Yes=0 No=1

5		Regarding your mental state during the last four weeks: Have you suffered from depression or fear? Psychological functioning:  Yes,   Yes,   Imited a   Ittle	Psychological func- tioning: 3P Life-enjoyment, happiness, success
		Accomplished less than you would like.  Did work or activities less carefully than usual.	
6	•	How much have physical and psychological issues affected your social contact with family, friends and neighbours in the last four weeks?  Psychological functioning/ Physical well-being  1 Not at all 2 A little bit 3 Moderately 4 Quite a bit 5 Extremely	Psychological functioning: 4P Physical well-being: 4P health, independence. Psychological functioning: Self-esteem, ability to communicate, life enjoyment
7	•	How strong (interfere) were your pain symptoms in the last four weeks? pain  1 No 2 Not at all 3 Alittle bit 4 Moderately 5 Quite a bit 6 Extremely	Pain: 5P 0-5
8		To what extent did pain symptoms hamper your day-to-day work in your profession or at home during the last four weeks? pain  1 Not at all 2 A little bit 3 Moderately 4 Quite a bit 5 Extremely	<b>Pain: 4P</b> 0-4
9	•	How often have physical and psychological issues hampered your contact with others during the last four weeks?  Psychological functioning category  Nervous, depressed, calm, exhausted, happy, tired, momentum, frustrated, full energy  1 All of the 2 Most of 3 Some of the 4 A little of the time 5 None of the time	Psychological functioning: Physical well-being 45 P (9P 0=5 1=good) Mental attitude. Happiness, Social and interpersonal well-being

10.	How did you feel du	ring t	he la	st fo	ur we	eks?			Physical well-be-
	Psychological functi	oning	g, Ph	ysica	l wel	l-beir	ng		ing:16 P
		All of	Most	A	Some	A	None		Symptom-free
		the time	of the time	good bit of the	of the time	little of the time	of the time		Psychological func-
				time					tioning:
	Have you felt calm & peaceful?	□¹	□	D <sub>3</sub>	D.	D <sub>s</sub>	□ <sub>s</sub>		16 P
	Did you have a lot of energy?			D.	D.	D <sub>i</sub>	□ <sub>6</sub>		Self-esteem, ability
	Have you felt down- hearted and blue?		D	D.	D.	D.			to adapt, adjust,
	Did you have any financial or material issue?		D.	D.	D.	D.	o.		cope
	51 H350H31 H350H								Financial and mate-
									rial well-being
11.	How would you de	scrib	e yo	ur cu	irrent	stat	e of	health?	Physical well-be-
	Physical well-being								ing: 4P
	☐1 Excellent ☐2 Very	/ Good	$\square_3$	Good	4	Fair	□5	Poor	Normal functional
									ability
12.	In the following you	will f	ind a	serie	s of s	tater	nent	s. Please	Psychological func-
	tick the appropriate	box	if apı	olicak	ole. P	ain, I	Psych	ological	tioning: 19P
	functioning, Physica	l wel	l-bei	ng					Physical well-be-
			1500		- 63				ing: 11P
			Yes		No				9 pain
				1					
				1					

TABLE 69: QUESTIONNAIRE EVALUATION IN COMPARISON WITH INTERVIEWS PER PATIENT (WITH AND WITHOUT ASV)

	with ASV	physical		physical ×0,111	painless			painless x 0,333	psycho- logical		psycho- logical x 0,167		physical x 0,111	painless x 0,333	psycho- logical x 0,167	interview x 0,25	Total/Interview/Pat.
11	XI EW2	625	0,111	69,4	223	0,333	X) EW2	74,3	303	0,166	50,3	XI EMS	69,4	74,3	50,3	58,25	233
12	XII FG	338	0,111	37,5	113	0,333	XIIFG	37,6	270	0,166	44,8	XIII	37,5	37,6	44,8	91,5	366
13	XIII FHJ	205	0,111	22,8	82	0,333	XIII FINS	27,3	174	0,166	28,9	X00 F90	22,8	27,3	28,9	50,25	201
14	XIV GR	462	0,111	51,3	120	0,333	XIVGR	40,0	307	0,166	51,0	XVGR	51,3	40,0	51,0	82	328
15	XV GB	312	0,111	34,6	155	0,333	xvga	51,6	244	0,166	40,5	nyga	34,6	51,6	40,5	46,25	185
16	XVI HW	362	0,111	40,2	90	0,333	MUM	30,0	224	0,166	37,2	XVI HW	40,2	30,0	37,2	68,5	274
17	XVII KI	185	0,111	20,5	113	0,333	XVER	37,6	152	0,166	25,2	XVIIII	20,5	37,6	25,2	36,25	145
18	XVIII KE	550	0,111	61,1	163	0,333	NO KE	54,3	269	0,166	44,7	EVENT	61,1	54,3	44,7	40,5	162
19	XIX KU2	561	0,111	62,3	212	0,333	XIX KUZ	70,6	249	0,166	41,3	XIX KU2	62,3	70,6	41,3	50,75	203
20	XX TH	275	0,111	30,5	88	0,333	XXTH	29,3	101	0,166	16,8	XX TH	30,5	29,3	16,8	54	216
				12,00		8,33		12,00		5	20,00					0.25	

	ASV	physical		physical × 0,111	painless			painless x 0,333	psycho- logical		psycho- logical x 0,167		physical x 0,111	painless x 0,333	psycho- logical x 0,167	Inter- view x 0,25	Total/ Inter- view/ Pat
1	I AK	437	0,111	48,51	198	0,333	I AJ.	65,93	223	0,166	37,02	I AJ.	48,51	65,93	49,47	73,75	295
2	II EW	335	0,111	37,19	223	0,333	II Ec.	74,26	215	0,166	35,69	II Ec.	37,19	74,26	43,99	15,25	61
3	III HD	658	0,111	73,04	178	0,333	III Ha.	59,27	332	0,166	55,11	III Ha.	73,04	59,27	67,56	61,25	245
4	IV KU	638	0,111	70,82	178	0,333	IV Ki.	59,27	391	0,166	64,91	IV Ki.	70,82	59,27	81,51	62,25	249
5	V NJ	681	0,111	75,59	223	0,333	V Ne.	74,26	376	0,166	62,42	V Ne.	75,59	74,26	79,02	87	348
6	VI SG	162	0,111	17,98	45	0,333	VI Schr.	14,99	126	0,166	20,92	VI Schr.	17,98	14,99	25,07	78,25	313
7	VII SB	684	0,111	75,92	223	0,333	VII Si.	74,26	398	0,166	66,07	VII Si.	75,92	74,26	82,67	94,75	379
8	VIII SH	260	0,111	28,86	148	0,333	VIII Sta.	49,28	208	0,166	34,53	VIII Sta.	28,86	49,28	46,98	58,75	235
9	DX TA	390	0,111	43,29	248	0,333	IX Te.	82,58	158	0,166	26,23	IX Te.	43,29	82,58	42,83	72,25	289
10	X PR	478	0,111	53,06	203	0,333	X Phi.	67,60	234	0,166	38,84	X Phi.	53,06	67,60	51,29	77	308
			100	12,00		8,33		12,00	18	5	20,00					0,25	

TABLE 70: DEMOGRAPHIC DATE EXCEL SHEET (OWN SOURCE) (1)

ID number	ASC without =0 with=1	Gender ( m/f )	Age	Family status m: married, p: partnership, a: alone	Km distance to practice	Social-status e: employed, s: self- employed, u: un- employed, r: retired	Date of interview dd.mm.yy
1SB	0	М	1963	a	15	е	11.08.16
2AK	0	М	1952	m	19	s	11.08.16
3SH	0	М	1952	а	10	u	24.08.16
4HD	0	М	1947	m	15	r	24.08.16
5TA	0	М	1940	m	24	r	24.08.16
6SG	0	F	1953	m	20	r	01.08.16
7KU	0	М	1960	a	15	е	06.12.16
8NJ	0	М	1953	а	19	r	06.12.16
9PR	0	М	1952	m	20	r	20.11.16
10EW	0	М	1940	m	18	r	17.11.16

TABLE 71: DEMOGRAPHIC DATE EXCEL SHEET (OWN SOURCE) (2)

ID .	ASC	Gender	Age	Family status	Km	Social status	Date of
number	without	( m/f )		m: married,	distance	e: employed,	interview
	=0			p: partnership,	to	s: self	dd.mm.yy
	with=1			a: alone	practice	employed,	
						u: un-	
						employed,	
						r: retired	
11FG	1	М	1949	m	16	S	23.03.17
12TH	1	F	1934	а	20	r	23.03.17
13GR	1	М	1935	m	28	r	23.03.17
14KI	1	F	1942	m	20	r	20.03.17
15EW	1	М	1932	р	12	r	24.03.17
16KE	1	F	1955	m	19	е	20.03.17
17KU	1	F	1944	m	12	r	06.03.17
18HW	1	М	1943	М	19	r	06.03.17
19FH	1	М	1943	р	20	r	20.03.17
20GB	1	М	1950	m	18	r	17.03.17

## Table 15: Example interview question B)

b) What outcome(s) do you hope will result from the completion of your treatment at this medical practice?

10PR: Hope means that all things will become good. I would like to travel a lot because that was what I liked for most of my life. Last year I was broken and felt depressed but now I accept the things as they are and feel better. I would like to travel in summer. I live my normal everyday life.

Coding category: sub node: hope, acceptance, continuity of support and worries.

### Table 16: Example interview question J)

j) Do you feel that you have been sufficiently informed about the possible side effects of your therapy? Information on side effects.

9AT: No, ... I work all day in my garden, mowing and chopping. Sometimes my grand-children can help,... but my wife is in hospital and I am alone at home, ...I do all the homework... cooking, cleaning, shopping ....I have two daughters but they have no time .. my wife requires an oxygen mask....I don't want to ask someone for help.

Coding category: far from practice social and personal conflicts. (He said nothing about the question and chattered about mowing his lawn and his family situation)

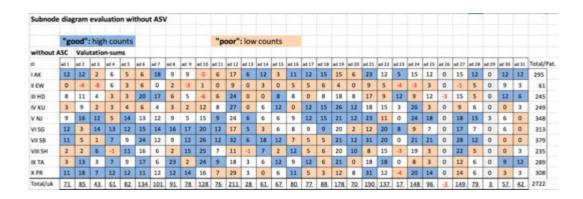
TABLE 72: NODE EVALUATION WITH AND WITHOUT ASC -3+3

with	K	appre	ciation o	doctor	- staff										S = S	um a to	o j
ASV	N	Grade	1 to 3:	-3 = 1	poor	2= mod	erate	+3= go	od								
PatId. I to X	K	1a	1b	1c	1d	1e	1f	1g	1h	11	1j	1k	11	1m	1n	10	s
XI EW	N	3															3
XII FG	K	1a	1b	1c	1d	1e	1f	1g	1h	1i	1j	1k	11	1m	1n	10	
	N			3	3	3	3	3	3	3	3	3	3		3		33
XIII FHJ		1a	1b	1c	1d	1e	1f	1g	1h	1i	1j	1k	11	1m	1n	10	
	N						3	3	3	3			3			3	18
XIV GR	K	1a	1b	1c	1d	1e	1f	1g	1h	1i	1j	1k	11	1m	1n	10	
	N				2			3	3								8
XV GB	K	1a	1b	1c	1d	1e	1f	1g	1h	1i	1j	1k	11	1m	1n	10	_
NATI LINA	N	10	41.	1.	4.4	1.	46	3	46	41	4:	41.	41	4	1.	1	3
XVI HW	K	1a	1b	1c	1d	1e	1f	1g	1h 3	1i 3	1j	1k	11	1m 3	1n	10	9
XVII KI	K	1a	1b	1c	1d	1e	1f	1g	1h	1i	1j	1k	11	1m	1n	10	. 9
ATII N	N	10	10	10	10	10	21	*6	3	21	-)	2	41	2111	211	10	5
XVIII KE	K	1a	1b	1c	1d	1e	1f	1g	1h	1i	1j	1k	11	1m	1n	10	_
	N										-						0
XIX KU	K	1a	1b	1c	1d	1e	1f	1g	1h	1i	1j	1k	11	1m	1n	10	
	N		1100000		3		100	3		-	12.77	1000	100	1000	1777177	3	9
XXTH	K	1a	1b	1c	1d	1e	1f	1g	1h	1i	1j	1k	11	1m	1n	10	
	N												3				3
		3	0	3	8	3	6	15	15	9	3	5	9	3	3	6	
Sum-grade per node																to 1	9:
Without	K	apprec	ciation o	loctor	- staff									S = Su	m at	oj	
ASV	N	Grade	1 to 3:	-3 = p	ooor	2= mod	erate	+3= go	od								S
PatId. I to X	K	1a	1b	1c	1d	1e	1f	1g	1h	1i	1j	1k	11	1m	1n	10	
IAK	N					3		3			3					3	12
		4.	45			3 33 3					-	41.					12
II EW	K	1a	1b	1c	1d	1e	1f	1g	1h	1i	1j	1k	11	1m	1n	10	
	N																0
III HD		1a	1b	1c	1d	1e	1f	1g	1h	1i	1j	1k	11	1m	1n	10	
	N			X 2000		1200		(200		2		500		3		3	8
IV KU	K	1a	1b	1c	1d	1e	1f	1g	1h	1i	1j	1k	11	1m	1n	10	-
V NJ	N K	1a	1b	1c	1d	10	1f	3 1g	1h	1i	11	1k	11	1m	1n	10	3
VIND	N	10	10	10	10	1e	11	3	- 111	11	1j	1K	3	TIII	TII	3	9
VI SG	K	1a	1b	1c	1d	1e	1f	1g	1h	1i	1j	1k	11	1m	1n	10	_
	N		-	2	2		2	2		2	~		2			-	12
VII SB	K	1a	1b	1c	1d	1e	1f	1g	1h	1i	1j	1k	11	1m	1n	10	
	N						3	2			3					3	11
VIII SH	K	1a	1b	1c	1d	1e	1f	1g	1h	1i	1j	1k	11	1m	1n	10	
	N															2	2
IXTA	K	1a	1b	1c	1d	1e	1f	1g	1h	1i	1j	1k	11	1m	1n	10	
W	N					-		-			3		41				3
X PR	K	1a	1b	1c	1d	1e	1f	1g	1h	1i	1j	1k	11	1m	1n	10	11
	N	0	0	2	5	3	7	3 16	3	4	9	0	- <del>3</del>	3	0	17	11
		U	U	2	5	3	/	10	3	4	9	U	2	3	U	17	

TABLE 73: ORIGINAL TABLE WITH AND WITHOUT ASV



TABLE 74: ORIGINAL TABLE (WITHOUT ASC)



# TABLE 75: ORIGINAL TABLE (WITH ASC)

Subnode o	diagra	n eval	luation	n with	ASV																											
		"goo	en top	-								*pee	r": low	counts																		
with ASC		Evalue	tion po	ints		_		_		-															_		_		_			Total
PM. ID	ad 1	ad 2	ad 3	ad 4	ad 5	ad 6	ad 7	ad B	ad 9	ad 10	ad 11	ad 12	ad 13	ad 34	ad 15	ad 26	ad 1.7	ad 18	ad 19	ad 20	ad 21	ad 22	ad 23	ad 24	ad 25	ad 26	ad 27	ad 28	ad 29	ad 30	ad 35	par
M EM	3	11	- 6	2		4	12		2	7	7	29	3	1	.6	2		8	14		25	3	0	22	28	0	37		0	0	1	231
XII FG	33	30	4	3.	3	26	19		8	34	11	-34		3	10	11	91	12	25	100	18	18	3	.22	13	0	20	3	0			36
XIII THE	18	38	15	0	7	9	9	1.	15	-2	3	22	3	5	12	4	3		9	1.	15	4	4	3	12	0	15	2	.0	3	0	20
XIV GR		30	6	2	4	14	36	6.	5	10	18	18	2	3		7	6		20		9	12	18	31	15	0	23	3	0	2	5	32
XV GB	3		9	0	5	6	3		6	11	6	18	3	4	3	12	3	15	3	1	3	6	5	137	6	0	12	3	0	2	0	18
WHW		12	237	22	.11	28	15	1.	16		12	26	4	12	5	5	6	-6	6	5	9	(2)	3	18	6	0	9	6	3	1	.0.	22
XVI KI	5	5	14	1	4	-2	0	2	13	10	2	13	1	1.2	- 3	1	1		7	-6	9	6	31	0	7	a	7	4	0	0		14
XVII KI		.7	-32	4	3	26	6	4	2	12	3	10	-2	- 1	-4	11	7.	-1	30.	4.	15	4	35	5.	7	0	25	-3			4	16
XIX KU		12	9	0	3	3	12	13	3	12	3	18		4	5	4	12	4	9	6	15	3	6	3	9	0	6	3	0	3.7	0	20
XX 194	3	20	7.	4	4	3	15	38	12	4	2	13	3	4	17	3	0	4	23		18		33	0	12	0		2.1	3	0	4	39
Sotal per mode		151.	85.	24.	51.	25.	112	22.	28.	92.	67.	184.	21.	40.	63.	62.	SZ	10.	132.	61.	128.	72.	65.	121.	107.	8	130.	65.	6.	22.	20.	2311

TABLE 76: CROSS DIAGRAM WITH ASV (INTERSECTION FOR "GOOD")

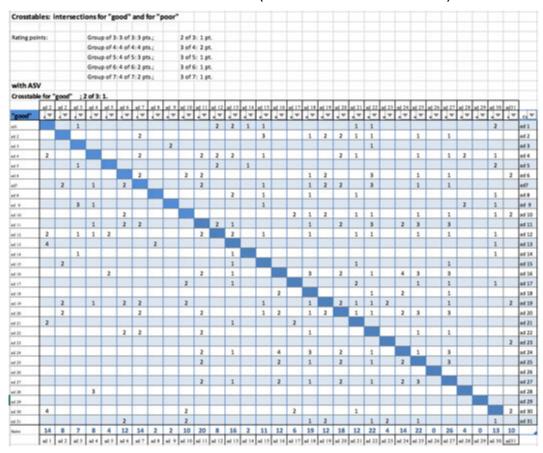


TABLE 77: CROSS DIAGRAM WITHOUT ASV (INTERSECTION FOR "GOOD")

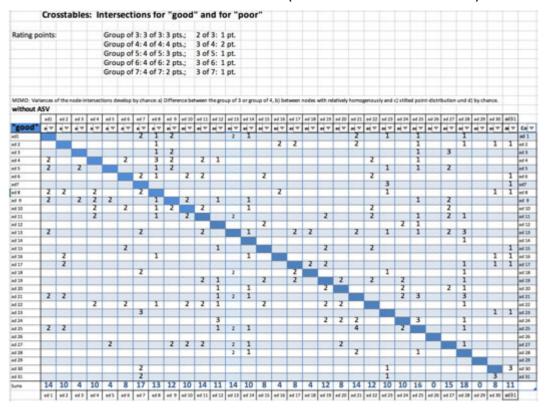


TABLE 78: CROSS DIAGRAM WITH ASV (INTERSECTION FOR "BAD)

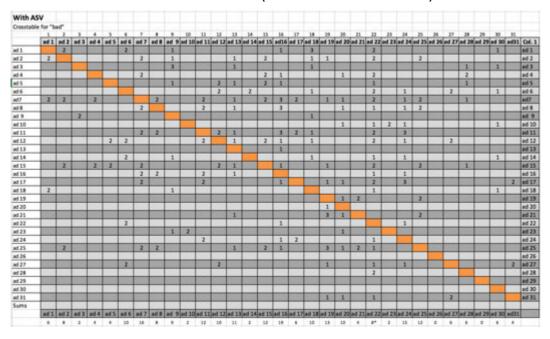


TABLE 79 CROSS DIAGRAM WITHOUT ASV (INTERSECTION FOR "BAD)

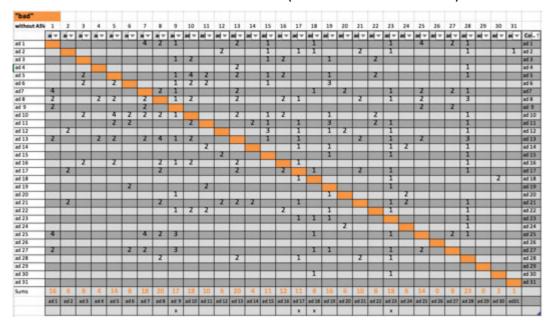


TABLE 80: SORT TABLE FOR GOOD (WITH ASC)

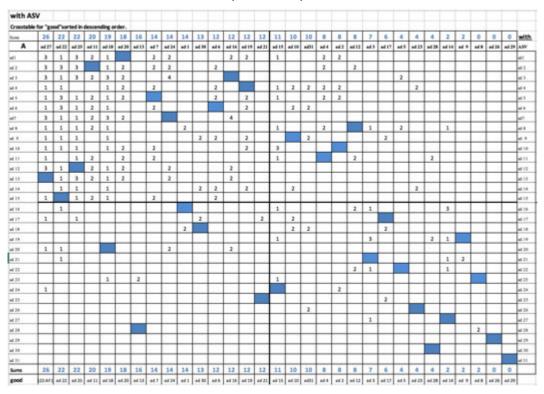


TABLE 81: SORT TABLE FOR GOOD (WITHOUT ASC)

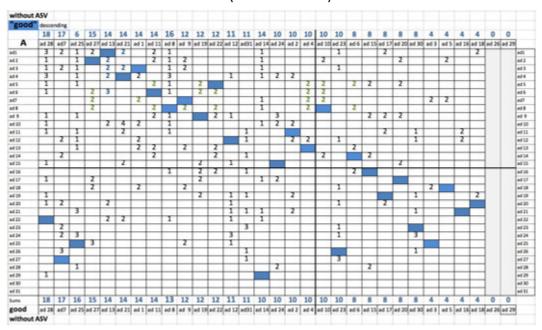


TABLE 82: SORT TABLE MAJOR COMPARISON (WITH AND WITHOUT ASC)

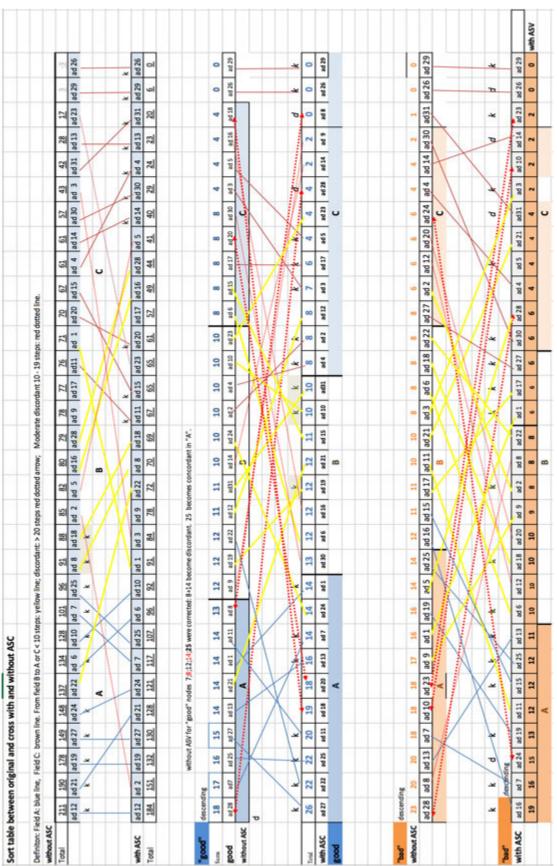


TABLE 83: SORT TABLE MAJOR COMPARISON

						with ASV		with ASV	with ASV
ad 26	Je 0	ad 29	-be	ad 29	di 66.26	ol se se	0 8 4 20		99 26
ad 29	>>,	10	- Ne	ad 26	1 52	9 5 3 6 W	ad 26		ad 29
11 ad 23	0	00	ise.	ad 23	11 52 99 12	2 1 2	0 8 pe 27 pe		ad 31
ad 13	1		/	1 ad31	# 25 #4 13	E 13	2 g g g g g g g g g g g g g g g g g g g		11 pe
28 26 31	4	10	/	2 ad 30	15 pa	지 경		~	4 4
31 E	1	8983		4 ad 14 k	Di S	Sil Si Si	4 ad 28	~   pl	ad 30
08 Pe	\ * ×	9d 30	· * V	A B A A	at 8	왕 X	ad 3 ad 28 ad 14	\$ U	ad 1.4
19 EF	lac ox	9d 20	HAI	ad 24	34 De	뒤일	2 S 7 2 2 2 2 2 2 2 2 2 2 2 2 2 2 2 2 2	W //	10000
Id b	14.	ad 17	N V	6 e d 20	a be	의 유	0 pe 4 17		87 pe
23 PR	XX	ad15 ad17 ad20 ad30	MM	6 6 6 6 6 6 6 6 6 6 6 6 6 6 6 6 6 6 6	23 pe	왕	ad3 ad 17 k k 17 k ad4 ad5	9	ad 16
30 52 61 61 22 63 30 20 ed 15 ad 4 ad 14 ad 30 ed 3	\/\\ <u>-</u>	100	$\langle \langle \chi \rangle \rangle$	9995	02 Pe	Ch Ch	The second secon		ad 17 a
11 Pg	W-1	_	W	84 18 ×	F1 F2	13 R	8 2 8 8 8 8 8 8 8 8 8 8 8 8 8 8 8 8 8 8		ad 20
at 11 /	WY	ad4 ad10 ad23	MXX	8 8 27	21 FF	20 20	20 de		ad 23 a
1 12	/ \/ <u>/</u>	ad 4	M	8 8 22 PR	ET ET	2		- / sl	ad 15 a
11 m	/ No	-	1-11)	9 gg	77 6 PR	13 pg 111 pg	10 ad 10 ad 31 ad 10 ad 31 ad 10 ad 31 ad	1 0 1 1 1	ad 11 a
22 PR	\ \\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\	100	14 W	Z g //	21 22 22 23	의 및	11 ad 15		ad 18 a
ad 16	W /s	ad 14		10 8 8 8 8	25 PR	50 88 80 100	12 × 8 B × 8	A STATE OF THE PARTY OF THE PAR	ad 8 be
al p	<b>W</b> /\	-	/X M	9114	14 °	2 2 2	ad 6 ad 16 ad 19 ad 21 ad 21 ad 21 ad 22 a	The second second	ad 22 a
2 ° E	N F	-	/ / / y	11 10 ad 11 ad 11 A	42	82 6 pr	21 12 14 19 14 15		e de
2 sed	V X F	9422	× \ /	= 15 -	21 Pd 28 Pd	지 및	21 2 3 4 1 2 8 8 8 8 8 8 8 8 8 8 8 8 8 8 8 8 8 8		ad 3 a
al 80 pg	$M/M_{\odot}$	0	×	21 Pg 34 16	a * 및	20 E	E 2		ad 1
ad 25 a	XX.	-	×//\	2 22 × //	St be	2d 8g	4 6 1 E	# <b>/</b>	ad 10 a
a 2	M	1		1 Sp 4	a n	81 0		8	
지양	////	ij,	MX	21.11.1		10 25 ×	1 1 2 A 1 E		ad 25 ad
1 9 P	(\ <mark>\</mark>   \		A X	16 16 ad 19 ad 19 k	12	3	16. 14 ad 13 ad 7 ad 25		_
22 8	N 2			A A	111 ed 22 e	121 M	ad 20	# \ \ \   E	124 00
2 2 2 2	/\/	d13 a	A	910	143 143 143 143 143 143 143 143 143 143	128 128 14	ad 18 a	21 4 22 E2	21 80
d 27 sc	<u> </u>	-		# 7 ×	142 nd 27 ad		20 ad 111 a	a A Bi	27 80
211 B	7/2	d 25 a		973	19 0	20 0	22 sed 25 se	T T T	ad 12 ad 2 ad 19 ad 27 ad 21 ad 24 ad 7
21 12 N	* 2	_	×	20 20 18 18 ad 8 ad 18 ad 10 ad 10	120 J	151 1	22 ad		2 2
221 150 178 149 148 123 138 139 100 ad 12 ad 21 ad 19 ad 27 ad 24 ad 22 ad 6 ad 10 ad 7	ex i	-	×	3d 28 a	211 130 113 ad 12 ad 21 ad 19 weth ASV internal	184 151 ad 12 ad 2	26 22 22 20 19 18 16 14 14 14 14 14 14 14 14 14 14 14 14 14	194 1	12 ad
		1 3			Total 215 150 12 ad 12 ad 21 ad 1 Commanicon with ASV Internal	Pe Pe			
Total without ASC	pood.	pool	"bad"	without ASC	Total	Total/uk	with ASC  "good"  Geocrating	Total	with ASV

TABLE 84: SORT TABLE BETWEEN ORIGINAL AND CROSS DIAGRAM

Overall comparison tabular					4	•	500	upper		8	c	middle	e	-	ر	0	lower	פֿב						discord	9	<b>+</b>	
Area comparison. subnodes 1 to 31			60	849		949	6	_				•	649				5 v 9	_			-	[5v9] 9	949 94	9v9 4v9		646	5v9
I. Originaltab. +/- ASV	1	2	m		2	7	00	6	10	::	12	13	14 1	5 16	5 17	18	19	20	21	22	23	24	25 26	5 27	28	59	30
A concordant 12, 21, 19,27,24,6,10,7,25	2				•	•			•		•			-	_		•		•			•	•	•			
B concordant 18, 22		Н	Н	Н	Н	Н	Н	Ц				П	Н	Н	Н	D		Ц		D	П	Н	Н				П
C concordant 11,15,20,13,14,30,4,31,29,26				0	-	_				0		0	0	0	_			0					0			0	0
discordant: non		H			Н	Н	Н								Н	Н	Ц						Н	Ц			
II: Crosstab. "good" +/-ASV	1	2	m	4	5 6	7	00	6	10	11	12	13	14	15 16	5 17	18	19	20	21	22	23	24	25 26	5 27	28	29	30
A concordant 27,22,25,11,13,7				H		•				•		•								•				•			
B concordant 19,10,31			-			_	200		C	563 533				+			C						-				
C concordant 4,2,3,17,5,26,29	733	0	0	0	0	L								H	0		-	Н					0			0	
discordant: 8,18,20,28						Н	<b>()</b>									0		()							H		
III: Crosstab. "poor" +/-ASV	1	2	3	4	2	7		6	10	11	12	13	14	15 16	5 17	18	19	-	21	22	23	24	25 26	5 27	28	29	30
A concordant 16,7,19,15,25,13		Н	H	Н	H	•	100	Ц		П		•		-		Ц	•				П		•	H			П
		a			D	_									D	D	COL										
C concordant 27,30,4,31,14,26,29			_	0	Н	Н	Н						0	Н	Н	Ц	Ц	Ц					0	0		0	0
discordant: 10,23,24,28			-	-		_			0					-	-						0	0			0		
IV. Originaltab. vs. "good" /- ASV	A		-	-	o	0		Ĭ	discord	_	0			-	_								-				
A concordant 7,25,27,21,8		Н	Н	Н	Н	•	•						Н	Н	H	Ц	Ц	Ц	•		П		•	•			
B concordant 2		a				1													1								
C concodant 4,23,15,17,20,30,26,29		Н	_	0		_								0	0			0			0	Н	0			0	
discordant: 13,18						Н						0				0	100										
V. Originaltab. vs. "poor" /- ASV	1	2	33	4	5 6	7	00	6	10	11	12	13	14	15 16	5 17	18	19	20	21	22	23	24	25 26	5 27	28	59	30
A concordant 8,7,10,19,5,25					•	•	•	5000	•								•						•				
		+	+		+	4	4	4		a	1	1		a	C	a						+	+	4			
C concordant 20,4,14,30,31,23,26,29		+	_	0	+	4	-	4					0	+	4	4	4	0			0		0			0	0
discordant: 12,24	1	1	+	+	+	+	+	-		1	-	-	-	$\rightarrow$	-	+	$\rightarrow$	-	-	1	1	-	+	+	-		
VI. Originaltab. vs. "good" /+ ASV	-	7	m	4	2	+	×	6	2	=	77	13	14	15 16	17	8	13	2	71	77	23	-	25 26	-	88	58	30
A concordant 27,24,7,25	1	+	+	+	+	•		1			1	+	+	+	+	4	4	1			1	•		•			T
B concordant 15	t	†	+	+		+	4	4		T	1	1	-	C	-	4	4	1			Ť	+	+	1			T
C concordant 17,28,5,14,4,29,26	1	†	+	0	0	+	+	1	1	T	*	*	0	+	0		4	1		1	Ť	†	0		0	0	T
discordant: 12,13	,	,	+	+	+	+	+	4	,	:	,	-	+	-	-	-	+	+	-		:	+	-	+	+	0	0
VII. Originaltab. vs. "poor / + ASV	4	7	2	4	0	1	0	D)	10	=	77	13	14	15 16	1	18		2	77	77	53	54	25 26	7	87	67	30
R concordant 18 9 8 17	İ	t	+	$^{+}$	+	+	1	-	I		•	t	+	+		-				I	T			+	1		T
C concordant 4.5.31.14.23.26.28.29.30	ţ	t	-	C	C	╀	1	+			T		C	╁	1	+	L	1			C	t	C		c	c	c
discordant: 13,16,21		t	-	Н	H	H	H	L		Γ		4		0		L	L	L	0			H	-	L	L		
VIII. "good" vs. "poor / - ASV	1	2	3	4	9	7	00	6	10	11	12	13	14	15 16	5 17	18	19	20	21	22	23	24	25 26	5 27	28	29	30
A concordant 28,7,25,13,8,9,19		H	Н	Н	Н	•		•		П		•	Н	Н	H	Н	•				П	000	•	Н	•		П
B concordant 2,22,24		D						5						_						C		D					
C concordant 20,30,18,26,29			H		H	H				П				H		0		0			П		0			0	0
discordant: non			H	Н										$\vdash$	$\overline{}$							$\overline{}$					
IX. "good" vs "poor" /+ ASV	1	2	m	4	9 9	7	00	6	10	11	12	13	14	15 16	5 17	18	19	20	21	22	23	24	25 26	5 27	28	29	30
A concordant 25,11,18,20,13,7,24			+	+	-	•				•		•		+	-	•	550					•	•	-			
B concordant 6,21					D									+					C								
C concordant 31,4,3,17,5,23,28,14,26,29	58		0	0	0	4	4	4			1		0	+	0						0		0		0	0	
						_																l	I				ı

TABLE 85: QUESTION EVALUATION ORIGINAL TABLE (WITH AND WITHOUT ASC)

Questi				-						LAS	•						
Field A:				8 highe				-									
Field C:	Node	s with	the 8	nowe	st poir	its of t	the ori	ginal t	able								
without	ASC	Rest	answ	ers to	aues	tions	2-0										
Question		a	Ь	c	d	e	f	g	h	i	j	k	1	m	n	0	
Questio	sum/				ŭ			Б			,		i i				
Field A	node				L												
6		3	3	14	9	5	11	19	13	16	12	7	17	12	14	12	
10		4	3	8	7	5	3	2	18	15	17	18	12	9	0	3	
12		11	5	2	8	14	21	21	23	20	27	15	15	9	3	14	
19		0	15	20	10	11	18	12	13	5	19	10	9	12	18	6	
21		5	11	9	5	14	6	21	21	8	17	6	17	20	9	21	
22		0	0	8	0	6	9	5	13	11	6	3	27	27	22	0	
24	9	3	3	6	8	6	10	15	9	3	5	12	14	21	18	15	
27		0	0	11	18	9	14	18	17	8	15	6	18	9	6	0	
Field A T	otal	26	40	78	65	70	92	113	127	86	118	77	129	119	90	71	without ASC
compari	son	37	39	30	66	55	101	93	99	84	60	36	122	78	45	100	with ASC
Questio	n	а	b	c	d	e	f	g	h	1	1	k	1	m	n	0	Sum
Field C to		-	-	-	-	-	_	ь			,	-	T.		-	-	5577
3	-	2	12	15	-1	-3	3	0	-2	8	2	0	0	5	0	2	43
4		9	6	8	0	3	5	6	3	2	7	7	0	2	0	3	61
13		0	0	0	0	7	0	0	16	5	0	0	0	0	0	0	28
14		0	0	0	0	3	8	0	0	6	3	3	26	6	6	0	61
15		0	0	0	6	9	17	6	3	0	3	2	6	15	0	0	67
23		-6	2	6	2	-3	0	3	-3	0	3	3	3	2	0	0	12
30		0	6	6	6	3	0	3	6	0	0	12	6	6	0	3	57
31		0	3	12	0	6	0	0	0	3	3	12	0	0	0	3	42
Field C		5	29	47	13	25	33	18	23	24	21	39	41	36	6	11	without ASC
		а	b	С	d	e	f	g	h	1	j	k	1	m	n	0	
compa	rison	2	25	20	3	13	7	3	42	18	-3	13	32	29	26	5	with ASC
Ougetie			ь		d		f	-	E I	i		k	1	-	_		Dumma-
Question		а	0	С	a	е	1	g	h	1	j	K	<u> </u>	m	n	0	iummen
Field C+	/-ASC	_	-		_	-	-	-	-	•	-	-	_	_	_	-	
4		9	6	8	0	3	5	6	3	2	7	7	0	2	0	3	61
13		0	0	0	0	7	0	0	16	5	0	0	0	0	0	0	28
14		0	0	0	0	3	8	0	0	6	3	3	26	6	6	0	61
30		0	6	6	6	3	0	3	6	0	0	12	6	6	0	3	57
31		0	3	12	0	6	0	0	0	3	3	12	0	0	0	3	42
Field C		9	15	26	6	22	13	9	25	16	13	34	32	14	6	9	without ASC

with A	SC	Best	answ	ers to	ques	tions	a bis	o (wit	h ASC	).								Nodes
Questio	Total	a	b	С	d	e	f	g	h	i	j	k	1	m	n	0	Sum	withou
Field A	Node																	ASC
2		0	6	3	10	9	16	14	17	18	13	3	11	15	6	10	151	6
7	2	0	6	1	5	7	18	15	13	9	3	1	17	3	0	19	117	10
12		10	0	6	16	8	15	17	20	12	25	7	21	9	6	12	184	12
19		15	15	11	6	10	14	5	14	13	5	4	13	0	0	6	131	19
21		9	9	0	3	0	9	15	9	15	0	3	17	15	9	15	128	21
24		3	3	6	8	6	10	15	9	3	5	12	14	21	18	9	142	22
25		0	0	0	0	6	5	9	0	6	6	0	11	15	0	29	87	24
27		0	0	3	18	9	14	3	17	8	3	6	18	0	6	0	105	27
A	31	37	39	30	66	55	101	93	99	84	60	36	122	78	45	100	with /	ASC
		$\leftrightarrow$	$\leftrightarrow$	1	$\leftrightarrow$	$\leftrightarrow$	$\leftrightarrow$	$\leftrightarrow$	$\leftrightarrow$	$\leftrightarrow$	1	1	$\leftrightarrow$	$\leftrightarrow$	1	$\leftrightarrow$		
comparis	on	26	40	78	65	70	92	113	127	86	118	77	129	119	90	71	withou	it ASC
Question	n	а	b	С	d	e	f	g	h	i	j	k	1	m	n	0		
vith ASC																		Node
Question	n	а	Ь	c	d	e	f	g	h	i	j	k	1	m	n	0	Sum	withou
Field C																		ASC
4		0	-3	10	0	6	0	0	3	5	0	0	0	3	0	0	24	3
5		2	22	1	0	4	1	0	3	5	-3	1	0	3	0	2	41	4
13		0	0	0	-3	0	0	0	24	2	0	0	0	0	0	0	23	13
14	/-	0	0	0	0	0	0	0	6	6	0	0	23	5	0	0	40	14
28		0	0	3	0	0	3	0	0	0	0	0	3	9	26	0	44	15
29	100	0	0	0	0	0	3	0	0	0	0	0	0	3	0	0	6	23
30		0	6	6	6	3	0	3	6	0	0	12	6	6	0	3	57	30
31	į.	0	0	0	-3	6	2	0	0	0	2	6	0	2	3	2	20	31
Field C	2	2	25	20	3	13	7	3	42	18	-3	13	32	29	26	5	with /	ASC
	8	$\leftrightarrow$	$\leftrightarrow$	$\leftrightarrow$	1	$\leftrightarrow$	1	1	1	$\leftrightarrow$	1	1	0	0	1	$\leftrightarrow$	235	
compari	son	5	29	47	13	25	33	18	23	24	21	39	41	36	6	11	witho	ut ASC
										7.0								

Field A		37	39	30	66	55	101	93	99	84	60	36	122	78	45	100	with A	sc
		$\leftrightarrow$	$\leftrightarrow$	1	$\leftrightarrow$	$\leftrightarrow$	$\leftrightarrow$	$\leftrightarrow$	$\leftrightarrow$	$\leftrightarrow$	1	1	$\leftrightarrow$	$\leftrightarrow$	\$	$\leftrightarrow$		
compari	son	26	40	78	65	70	92	113	127	86	118	77	129	119	90	71	withou	t ASC
Questio	n	а	b	С	d	e	f	g	h	i	j	k	1	m	n	0		
Concor	dant n	odes	in F	ield A	: 12	. 19.	21.2	4 27										
without				ers to														
Question		a	b	c	d	e	f		h	ī		k	T					
Questio	sum/	a			u	e		g			j	, N	-	m	n	0		
Field A																		
12		11	5	2	8	14	21	21	23	20	27	15	15	9	3	14		
19		0	15	20	10	11	18	12	13	5	19	10	9	12	18	6		
21		5	11	9	5	14	6	21	21	8	17	6	17	20	9	21		
24		3	3	6	8	6	10	15	9	3	5	12	14	21	18	15		
27	1.	0	0	11	18	9	14	18	17	8	15	6	18	9	6	0		
Field A T	otal	19	34	48	49	54	69	87	83	44	83	49	73	71	54	56	witho	ut ASC
compari	son	37	27	26	51	33	62	55	69	51	38	32	83	45	39	42	with A	sc
Concor	dant n	odes	in E	ield A	. 12	10	21 2	4 27										
with A				ers to					h ACC									Nodes
	1														-	-	6	
Questio		9	b	С	d	е	f	g	h	i	j	k	- 1	m	n	0	Sum	withou
Field A	Node	10	_	-	16	_	45	47	20	42	25	-		_	_	12	***	ASC
12	-	10	15	11	16	10	15	<b>17</b>	20	12	<b>25</b>	7	13	9	6	6	184	12 19
21	_	9	9	0	3	0	9	15	9	15	0	3	17	15	9	15	128	21
24		3	3	6	8	6	10	15	9	3	5	12	14	21	18	9	142	22
27		0	0	3	18	9	14	3	17	8	3	6	18	0	6	0	105	27
A	Ċ.	37	27	26	51	33	62	55	69	51	38	32	83	45	39	42	with A	
^		↔	← →	\$	$\leftrightarrow$	↔	↔	<b>↔</b>	↔	$\leftrightarrow$	1	↔	$\leftrightarrow$	↔	$\leftrightarrow$	↔	WILLIA	50
comparis	on	19	34	48	49	54	69	87	83	44	83	49	73	71	54	56	withou	+ ASC
Question	200	a	b	c	d	e	f	g	h	i	j	k	1	m	n	0	Withou	1
Concor	dant n	odes	in F	ield C	:4.	13. 1	4.30.											
without							,											
Question	n	а	ь	С	d	e	f	g	h	i	1	k	1	m	n	0	Sum	
Field C wi			-		-	-	<u> </u>	ь			,	-	i i			-		
4	Lilout M	9	6	8	0	3	5	6	3	2	7	7	0	2	0	3	61	
13		0	0	0	0	7	0	0	16	5	0	0	0	0	0	0	28	
14	7	0	0	0	0	3	8	0	0	6	3	3	26	6	6	0	61	
30		0	6	6	6	3	0	3	6	0	0	12	6	6	0	3	57	
31		0	3	12	0	6	0	0	0	3	3	12	0	0	0	3	42	
Field C		9	15	26	6	22	13	9	25	16	13	34	32	14	6	9	witho	
	1				-													
with ASC		7			- 4		70.00	1 23	200									
Question		а	b	C	d	e	f	g	h	i	j	k	E	m	n	0	Sum	
Field C w	ith ASC														_			
4	-	0	-3	10	0	6	0	0	3	5	0	0	0	3	0	0	24	
13	-	0	0	0	-3	0	0	0	24	2	0	0	0	0	0	0	23	
14	2	0	0	0	0	0	0	0	6	6	0	0	23	5	0	0	40	
30		0	6	6	6	3	0	3	6	0	0	12	6	6	0	3	57	
31	9	0	0	0	-3	6	2	0	0	0	2	6	0	2	3	2	20	
		_						_				_	_			_		

## TABLE 86: QUESTION EVALUATION CROSS TABLE (WITH AND WITHOUT ASV)

## Question- evaluation cross diagram with and without ASC

Field A: Nodes with high intersection for "good" Field C: Nodes with low intersection for "good"

Question		a	b	c	d	e	f	g	h	i	j	k		m	n	0
	sum/	100	_	46700	(5)	7	23.0	ľ	1,250	15%	_ ^ _		100	1,25555	0.000	100
Field A	node															
1		0	0	2	5	3	7	16	3	4	9	0	2	3	0	17
7		0	3	2	3	6	3	15	20	6	3	0	17	6	0	17
8		16	4	3	0	3	6	12	8	6	9	3	5	5	0	9
11		0	0	0	0	0	25	19	0	0	0	0	23	9	0	0
13	1	0	0	0	0	7	0	0	16	5	0	0	0	0	0	0
19		0	15	20	10	11	18	12	13	5	19	10	9	12	18	6
21		5	11	9	5	14	6	21	21	8	17	6	17	20	9	21
22		0	0	8	0	6	9	5	13	11	6	3	27	27	22	0
25		0	0	0	0	6	5	3	3	6	6	3	11	15	3	29
27		0	0	11	18	9	14	18	17	8	15	6	18	9	6	0
28		0	0	0	0	3	9	3	0	0	0	0	12	28	24	0
Field A Total		21	33	55	41	68	102	124	114	59	84	31	141	134	82	99
comparison		9	12	13	54	37	74	88	115	70	41	30	102	97	45	76
Question		а	b	С	d	e:	f	g	h	i	j	k	1	m	n	0
Field C tota	al			0 0			Y - X			1					0 0	
2		3	0	0	3	5	14	11	3	7	0	2	13	13	2	9
3		2	12	15	-1	-3	3	0	-2	8	2	0	0	5	0	2
4		6	3	8	0	3	5	6	3	2	7	7	0	2	0	3
5		3	14	17	5	6	0	3	9	6	3	5	2	3	0	6
6		3	3	14	9	5	11	19	13	16	12	7	17	12	14	12
15		0	0	0	6	9	17	6	3	0	3	2	6	15	0	0
16		3	12	15	7	6	0	0	5	14	6	6	0	6	0	0
17		0	0	11	21	15	0	3	12	6	3	0	6	0	0	0
18		0	0	12	17	3	6	9	14	6	12	0	9	0	0	0
20		0	0	0	0	0	19	3	0	-3	0	0	6	23	13	9
30		0	6	6	6	3	0	3	6	0	0	12	6	6	0	3
Field C		20	50	98	73	52	75	63	66	62	48	41	65	85	29	44
without ASC		1	$\leftrightarrow$	· +												
			_	_	_	_	_	_				_	_	_		_

0 3 6	0 3 12	3 0 10	18 0 46	9 0 34	0 68	3 0 73	17 3 100	61	38	3 25	93	94	42	70
_	-	_	7.7	-	-			_				-		
0	0	3	18	9	14	3	1/	0	3	0	10	0	-	~
				-		-		8	3	6	18	0	6	0
0	0	0	0	6	5	9	0	6	6	0	11	15	0	29
3	3	6	8	6	10	15	9	3	5	12	14	21	18	9
0	0	0	0	0	0	3	9	6	3	3	15	30	3	0
0	0	0	3	0	8	3	0	6	0	0	5	17	16	3
_ 0	0	0	12	3	0	6	21	9	12	0	6	0	0	0
0	0	0	-3	0	0	0	24	2	0	0	0	0	0	0
0	0	0	3	3	13	19	4	9	3	0	7	2	-3	7
0	6	1	5	7	18	15	13	9	3	1	17	3	0	19
de de	1 "	٠	0	e		8	"		, ·	, ×	'	m	п	0
	tal a de 0 0 0 0 0 0 0 0 3	tal a b de 0 6 0 0 0 0 0 0 0 0 0 0 0 0 0 0 0 0 0	tal a b c de 0 6 1 0 0 0 0 0 0 0 0 0 0 0 0 0 0 0 0 0	tal a b c d de 0 6 1 5 0 0 0 3 0 0 0 -3 0 0 0 0 12 0 0 0 0 3 0 0 0 0 0 3 3 6 8 0 0 0 0 0	tal a b c d e  de 0 6 1 5 7  0 0 0 3 3  0 0 0 -3 0  0 0 0 12 3  0 0 0 0 3 0  0 0 0 0 0 0  3 3 6 8 6  0 0 0 0 0 6	tal a b c d e f  de 0 6 1 5 7 18  0 0 0 0 3 3 13  0 0 0 0 -3 0 0  0 0 0 12 3 0  0 0 0 0 3 0 8  0 0 0 0 0 0 0 0  3 3 6 8 6 10  0 0 0 0 0 6 5	tal     a     b     c     d     e     f     g       de     0     6     1     5     7     18     15       0     0     0     0     3     3     13     19       0     0     0     0     0     0     0     0       0     0     0     12     3     0     6       0     0     0     3     0     8     3       0     0     0     0     0     0     3       3     3     6     8     6     10     15       0     0     0     0     6     5     9	de	tal     a     b     c     d     e     f     g     h     i       de     0     6     1     5     7     18     15     13     9       0     0     0     0     3     3     13     19     4     9       0     0     0     0     0     0     24     2       0     0     0     12     3     0     6     21     9       0     0     0     0     0     3     9     6       0     0     0     0     0     3     9     6       3     3     6     8     6     10     15     9     3       0     0     0     0     6     5     9     0     6	tal         a         b         c         d         e         f         g         h         i         j           de         0         6         1         5         7         18         15         13         9         3           0         0         0         0         3         3         13         19         4         9         3           0         0         0         0         0         0         24         2         0           0         0         0         12         3         0         6         21         9         12           0         0         0         0         0         3         9         6         3           3         3         6         8         6         10         15         9         3         5           0         0         0         0         6         5         9         0         6         6	tal         a         b         c         d         e         f         g         h         i         j         k           de         0         6         1         5         7         18         15         13         9         3         1           0         0         0         0         3         3         13         19         4         9         3         0           0         0         0         -3         0         0         0         24         2         0         0           0         0         0         12         3         0         6         21         9         12         0           0         0         0         3         0         8         3         0         6         0         0           0         0         0         0         0         3         9         6         3         3           3         3         6         8         6         10         15         9         3         5         12           0         0         0         0         6         5         9         0	tal         a         b         c         d         e         f         g         h         i         j         k         I           de         0         6         1         5         7         18         15         13         9         3         1         17           0         0         0         0         3         3         13         19         4         9         3         0         7           0         0         0         -3         0         0         0         24         2         0         0         0           0         0         0         12         3         0         6         21         9         12         0         6           0         0         0         3         0         8         3         0         6         0         0         5           0         0         0         0         0         3         9         6         3         3         15           3         3         6         8         6         10         15         9         3         5         12         14	tal         a         b         c         d         e         f         g         h         i         j         k         l         m           de         0         6         1         5         7         18         15         13         9         3         1         17         3           0         0         0         0         3         3         13         19         4         9         3         0         7         2           0         0         0         -3         0         0         0         24         2         0         0         0         0           0         0         0         12         3         0         6         21         9         12         0         6         0           0         0         0         3         0         8         3         0         6         0         0         5         17           0         0         0         0         0         3         9         6         3         3         15         30           3         3         6         8         6         10	tal         a         b         c         d         e         f         g         h         i         j         k         l         m         n           de         0         6         1         5         7         18         15         13         9         3         1         17         3         0           0         0         0         0         3         3         13         19         4         9         3         0         7         2         -3           0         0         0         -3         0         0         0         24         2         0         0         0         0         0           0         0         0         12         3         0         6         21         9         12         0         6         0         0           0         0         0         3         0         6         21         9         12         0         6         0         0           0         0         0         0         0         3         9         6         3         3         15         30         3

a b c d e f g h i j k l m n o

## Concordant notes field A: 7, 11, 13, 22, 25, 27

without AS	SC	Besta	nswer	s to qu	estions	a-0							200000		v2	
Question Field A	sum/ node	а	ь	c	d	e	f	g	h	i	j	k	1	m	n	0
7		0	3	2	3	6	3	15	20	6	3	0	17	6	0	17
11		0	0	0	0	0	25	19	0	0	0	0	23	9	0	0
13		0	0	0	0	7	0	0	16	5	0	0	0	0	0	0
22		0	0	8	0	6	9	5	13	11	6	3	27	27	22	0
25		0	0	0	0	6	5	3	3	6	6	3	11	15	3	29
27		0	0	11	18	9	14	18	17	8	15	6	18	9	6	0
Field A Total		0	3	21	21	34	56	60	69	36	30	12	96	66	31	46
comparison		0	6	4	23	25	50	49	67	40	18	10	68	50	6	55

## Concordant notes field A: 7, 11, 13, 22, 25, 27

with ASC		Besta	nswer	s to qu	estions	a bis o	(with	ASC).								
Question Field A	Total Node	а	ь	с	d	e	f	g	h	i	j	k	1	m	n	0
7		0	6	1	5	7	18	15	13	9	3	1	17	3	0	19
11		0	0	0	3	3	13	19	4	9	3	0	7	2	-3	7
13		0	0	0	-3	0	0	0	24	2	0	0	0	0	0	0
22		0	0	0	0	0	0	3	9	6	3	3	15	30	3	0
25	1	0	0	0	0	6	5	9	0	6	6	0	11	15	0	29
27		0	0	3	18	9	14	3	17	8	3	6	18	0	6	0
Field A		0	6	4	23	25	50	49	67	40	18	10	68	50	6	55
with ASC		$\leftrightarrow$	$\leftrightarrow$	1	$\leftrightarrow$	1	$\leftrightarrow$									
comparison		0	3	21	21	34	56	60	69	36	30	12	96	66	31	46
Question		а	b	С	d	e	f	g	h	i	j	k	1	m	n	0

Question	а	b	c	d	e	f	g	h	1	j	k	1	m	n	0
Field C															
2	0	6	3	10	9	16	14	17	18	13	3	11	15	6	10
3	9	16	22	1	8	3	-3	9	11	3	3	0	1	0	1
4	0	-3	10	0	6	0	0	3	5	0	0	0	3	0	0
5	2	22	1	0	4	1	0	3	5	-3	1	0	3	0	2
8	15	5	3	3	3	6	3	3	5	3	2	3	0	0	16
9	14	13	17	3	11	6	0	5	7	0	5	0	-3	0	0
12	10	0	6	16	8	15	17	20	12	25	7	21	9	6	12
14	0	0	0	0	0	0	0	6	6	0	0	23	5	0	0
17	0	0	0	12	10	3	7	12	4	3	0	6	0	0	0
23	-4	5	6	2	-3	0	3	-3	0	3	3	3	2	0	0
28	0	0	3	0	0	3	0	0	0	0	0	3	9	26	0
Field C	46	64	71	47	56	53	41	75	73	47	24	70	44	38	41
22-1	1	$\leftrightarrow$	(												
omparison	20	50	98	73	52	75	63	66	62	48	41	65	85	29	44
	a	b	c	d	e	f	g	h	i i	i	k	1	m	n	0

Concordant	notesfield	C: 3. 4. 17

			.,												
Question	а	b	С	d	e	f	g	h	i	j	k	1	m	n	0
Field C total							J-100			1,000					
3	2	12	15	-1	-3	3	0	-2	8	2	0	0	5	0	2
4	6	3	8	0	3	5	6	3	2	7	7	0	2	0	3
17	0	0	11	21	15	0	3	12	6	3	0	6	0	0	0
Field C	8	15	34	20	15	8	9	13	16	12	7	6	7	0	5
without ASC	$\leftrightarrow$	. \$	$\leftrightarrow$												
comparison	9	13	32	13	24	6	4	24	20	6	3	6	4	0	1

## Concordant notes field C: 3, 4, 17

with ASC	12	20 20		20 000	200. 10	2	200 100	2	24 - 60		2	200 190		20 000	
Question	a	b	c	d	e	f	g	h	i	j	k	1	m	n	0
Field C			0.00				502.0			200			007		
3	9	16	22	1	8	3	-3	9	11	3	3	0	1	0	1
4	0	-3	10	0	6	0	0	3	5	0	0	0	3	0	0
17	7 0	0	0	12	10	3	7	12	4	3	0	6	0	0	0
Field C	9	13	32	13	24	6	4	24	20	6	3	6	4	0	1
	$\leftrightarrow$	1	$\leftrightarrow$												
comparison	8	15	34	20	15	8	9	13	16	12	7	6	7	0	5
	a	b	c	d	e	f	g	h	1	j	k	1	m	n	0

Field A	9	12	13	54	37	74	88	115	70	41	30	102	97	45	76
• (0.000,000,000)		1	1	$\leftrightarrow$	1	$\leftrightarrow$	$\leftrightarrow$	$\leftrightarrow$	$\leftrightarrow$	1	$\leftrightarrow$	$\leftrightarrow$	$\leftrightarrow$	\$	$\leftrightarrow$
comparison	33	46	67	43	71	105	127	122	64	91	39	141	131	85	101
Question	а	b	С	d	e	f	g	h	i	j	k	1	m	n	0

Field C	20	50	98	73	52	75	63	66	62	48	41	65	85	29	44
	1	$\leftrightarrow$	$\leftrightarrow$		$\leftrightarrow$		1		$\leftrightarrow$		$\leftrightarrow$	1	$\leftrightarrow$	1	1.
comparison	33	46	67	43	71	105	127	122	64	91	39	141	131	85	101
	_ \$	\$	1	$\leftrightarrow$	1	$\leftrightarrow$	$\leftrightarrow$	$\leftrightarrow$	$\leftrightarrow$	1	$\leftrightarrow$	$\leftrightarrow$	$\leftrightarrow$	1	$\leftrightarrow$
Field A	9	12	13	54	37	74	88	115	70	41	30	102	97	45	76
S N		1	1	$\leftrightarrow$	$\leftrightarrow$	$\leftrightarrow$	1	$\leftrightarrow$	$\leftrightarrow$	$\leftrightarrow$	$\leftrightarrow$	$\leftrightarrow$	\$	$\leftrightarrow$	1
Field C	46	64	71	47	56	53	41	75	73	47	24	70	44	38	41

# TABLE 87: QUESTIONNAIRE ASSESMENT TABLE WITH ASC

Questio	onaire evaluation table					
	Physical performance Ph		Painlessness PI	Psychol	logical well-being	Ps
with	F 9 to 12 questions with physical aspects		F 3 to 12 questions, aspects relatet to pain	F	5 to 12 questions, psycological aspects	
ASC	N (Evaluation points (yes-0-bad; no-1-good)		N (Evaluation points (yes-0-bad ; no-1-good)	N S	Evaluation points	
	M max, points per questions		M (max, points per questions	M I	max, points per questions	
Part, Id.		100	100 100 100		100 100 100 100 100	ı
XII EW2	F   1 2 3 4 6 9 10 11	12	F   7 8 12	F	5 6 9 10 12	
	N 2 3 12 4 4 3 10 3	11	N 5 4 9	N I	1 4 28 10 18	
	M 4 4 20 4 4 4 16 4	39	M 5 4 39	M	3 4 45 16 39	
		100	Nx100 500 400 900	Mx100	100 400 2800 1000 1800 33 100 62 62 46	
	% \$ 50 75 60 100 100 75 62 75 100 100 100 100 100 100 100 100 100	28 625	% 100 100 23 223	% ;	33 100 62 62 46 100 100 100 100 100	303
XII FG	F 1 1 2 3 4 6 9 10 11	12	F   7 8 12	F 1	5 6 9 10 12	
10.10	N 2 2 6 0 2 2 7 2	6	N 2 2 9	N I	3 2 20 7 13	
	M 4 4 20 4 4 4 16 4	39	M 5 4 39	M	3 4 45 16 39	
		600	Avi 00 200 200 900	Mx100	300 200 2000 700 1300	
	% 50 50 30 0 50 50 43 50	15 338	% 40 50 23 113	%	100 50 44 43 33	270
	100 100 100 100 100 100 100 100	100	100 100 100		100 100 100 100 100	
XIII FHS	N 1 0 2 0 0 3 11 1	12	F 7 8 12 N 2 1 7	, n	5 6 9 10 12 0 0 27 11 18	l
	M 4 4 20 4 4 4 16 4	39	M 5 4 39	l ñ	0 0 27 11 18 3 4 45 16 39	l
		100	Nx100 200 100 700	Aut 00	0 0 2700 1100 1800	l
	% 25 0 10 0 0 75 68 25	2 205	% 40 25 17 82	%	0 0 60 68 46	174
	100 100 100 100 100 100 100 100	100	100 100 100		100 100 100 100 100	
XIV GR	1 1 2 3 4 6 9 10 11	12	7 8 12	,	5 6 9 10 12	
	N 3 2 1 0 4 4 8 3	3	N 5 0 8	l N	3 4 10 8 14	l
	M 4 4 20 4 4 4 16 4	39	M 5 4 39	M	3 4 45 16 39	
	Nx100 300 200 100 0 400 400 800 300 % 75 50 5 0 100 100 50 75	7 462	Nation 500 0 800 Nation 100 0 20 120	Mx100	300 400 1000 800 1400 100 100 22 50 35	307
		100	100 100 100	~ 1	100 100 100 100 100	307
XV GB	1 2 3 4 6 9 10 11	12	F : 7 8 12	F :	5 6 9 10 12	
	N 2 3 1 0 2 1 6 2	8	N 3 3 8	N I	2 2 24 6 15	
	M 4 4 20 4 4 4 16 4	39	M 5 4 39	M	3 4 45 16 39	
		800	Ax100 300 300 800	Mx100	200 200 2400 600 1500	
	% \$ 50 75 5 0 50 25 37 50	20 312	% 60 75 20 155	% 1	66 50 53 37 38 100 100 100 100 100	244
XVI HW		100	F 1 7 B 12			
ANTIMAY	N 1 1 2 3 4 6 9 10 11 N 1 1 1 18 0 4 2 6 1	12	N 3 0 12	l n	5 6 9 10 12 0 4 26 6 12	
	M 4 4 20 4 4 4 16 4	39	M 5 4 39	M	3 4 45 16 39	
		400	Avi 00 300 0 1200	Aktion	0 400 2600 600 1200	
	% 25 25 90 0 100 50 37 25	10 362	% 60 0 30 90	%	0 100 57 37 30	224
XVII KI		100	100 100 100 F 1 7 8 12	- 1	100 100 100 100 100	
AVE KI	F 1 2 3 4 6 9 10 11 N 1 0 4 0 2 1 4 1	6	F 7 8 12 N 2 2 9	l n	5 6 9 10 12 0 2 20 4 13	l
	M 4 4 20 4 4 4 16 4	39	M 5 4 39	i iii	3 4 45 16 39	l
		600	Nx100 200 200 900	Mx100	0 200 2000 400 1300	l
	% 25 0 20 0 50 25 25 25	15 185	% 40 50 23 113	%	0 50 44 25 33	152
	100 100 100 100 100 100 100 100	100	100 100 100		100 100 100 100 100	
XVIII KE	1 1 2 3 4 6 9 10 11	12	7 8 12		5 6 9 10 12	
	N 2 4 8 1 4 3 10 3 M 4 4 20 4 4 4 16 4	9	N 2 4 9 M 5 4 39	N N	0 4 30 10 16 3 4 45 16 39	l
		39	M 5 4 39 Nx100 200 400 900	Mx100	3 4 45 16 39 0 400 3000 1000 1600	l
	Nx100 200 400 800 100 400 300 1000 300 % 50 100 40 25 100 75 62 75	23 550	% 40 100 23 163	%	0 100 66 62 41	269
		100	100 100 100		100 100 100 100 100	
XXX KU2	1 1 2 3 4 6 9 10 11	12	F 7 8 12	F 1	5 6 9 10 12	
	N 2 3 18 2 4 2 11 2	11	N 5 4 5	N I	0 4 23 11 12	l
	M 4 4 20 4 4 4 16 4	39	M 5 4 39	M	3 4 45 16 39	l
	Wx100 200 300 1800 200 400 200 1100 200 1	100	Nx100 500 400 500	Mx100	0 400 2300 1300 1200	l
	% 50 75 90 50 100 50 68 50 100 100 100 100 100 100 100 100	28 561	% 100 100 12 212	%	0 100 51 68 30 100 100 100 100 100	249
XX TH	1 2 3 4 6 9 10 11	12	F 7 8 12	F 1	5 6 9 10 12	
AR 111	N 1 0 1 13 0 4 2 4 0	4	N 2 1 9	1 6 1	0 0 21 4 12	l
	M 4 4 20 4 4 4 16 4	39	M 5 4 39	M	3 4 45 16 39	l
		400	Nx1000 200 100 900	Mx100	0 0 2100 400 1200	l
	% 0 25 65 0 100 50 25 0	10 275	% 40 25 23 88	%	0 0 46 25 30	101
	N: from 39 answers in item 12 where 11 answers relatet to P	. 9 to Pl an	d 19 to Ps.			

TABLE 88: QUESTIONNAIRE ASSESSMENT TABLE WITHOUT ASC

Questionaire	eval	uatio	n tab	ole																					
Questionaire	Physic	al per	form	ance		Ph							Painl	essne	ss		PI		Psyc	hologi	cal we	II-bein	эг		
without	Q	9 to 1	2 ques	tions w	ith phy	ysical a	spects					Q	3 to 1	2 Quest	tions w	vith asp	pects re	elatet to pain	Q	5 to 1	2 Quest	tions w	ith psy	cologic	al aspe
ASC	N	Evalu	ation p	ooints (	yes=0=	bad; n	o =1=g	(bood)				N	Evalu	ation p	oints (y	res=0=i	bad ; n	o =1=good)	N	Evalue	rtion po	oints (y	es=0-b	ad; no	=1=gc
	М	max.	points	per qu	estions						_	м	max.	points (	per que	estions	_		м	max.	points p	per que	stions	_	_
	a	1	2	3	4	6	9	10	11	12			a	7	*	12	ш		Q	5	6	9	30	12	ΙI
IAL	N	2	1	14	1	3	3	8	2	7			N	5	3	9	ш		N	0	3	25	8	17	H
	м	4	4	20	4	4	4	16	4	39			м	5	4	39			м	3	4	45	16	39	H
	RF200	200	100	1400	100	300	300	800	200	700			Niv (100)	500	300	900			A+100	0	300	2500	800	1700	H
	%	50	25	70	25	75	75	50	50	17	437		%	100	75	23	198		%	0	75	55	50	43	223
		100	100	100	100	100	100	100	100	100			_	100	100	100	-			100	100	100	100	100	Н
II Ec.	Q. N	1	2	10	0	3	2	6	8	9			Q N	5	4	3 9	0		Q	5	6	9	30	12	ΙI
	M	1	4	20	4	4	4	16	4	39			M	5	4	39			N M	0	3	25 45	6 16	19 39	H
	NVT00	100	100	1000	0	300	200	600	200	900			AV100	500	400	900	ш		A+100	0	300	2500	600	1900	ΙI
	%	25	25	50	0	75	50	37	50	23	335		%	100	100	23	223		%		75	55	37	48	215
		100	100	200	100	100	100	100	100	100	200			100	200	100	100		- "	100	100	100	100	100	
III Ha.	q	1	2	3	4	5	6	7	8	9	-		q	1	2	3	0		Q	5	6	9	30	12	Н
	N	2	1	17	1	3	3	7	11	2			N	4	3	9			N	3	3	30	7	19	ΙI
	м	4	4	20	4	4	4	16	4	39			м	5	4	39			м	3	4	45	16	39	H
	Ni-200	200	100	1700	100	300	300	700	2100	200			N:100	400	300	900	ш		A+100	300	300	3000	700	1900	ΙI
	%	50	25	85	25	75	75	43	275	5	658		%	80	75	23	178		%	100	75	66	43	48	332
		100	100	200	100	100	200	100	100	200				100	200	100				100	200	100	100	200	П
IV Ki.	Q	1	2	3	4	5	6	7	8	9			Q	1	2	3			Q	5	6	9	30	12	П
	N	2	2	17	4	4	4	12	2	11			N	4	3	9	ш		N	3	4	31	12	19	ΙI
	м	4	4	20	4	4	4	16	4	39			м	5	4	39	ш		м	3	4	45	36	39	H
	Nr:200	200	200	1700	400	400	400	1200	200	1100			AH100	400	300	900	ш		A+100	300	400	3100	2200	1900	H
	%	50	50	85	100	100	100	75	50	28	638		%	80	75	23	178		%	100	100	68	75	48	391
		100	100	200	100	100	200	100	100	200	$\vdash$			100	200	100	ш		_	100	200	100	100	200	Ш
V Ne.	Q	1	2	3	4	5	6	7	8	9			Q	1	2	3	ш		Q	5	6	9	10	12	ΙI
	N	2	3	17	4	4	4	11	3	11			N	5	4	9	ш		N	3	4	28	11	18	ΙI
	M	4	4	20	4	4	4	16	4	39			M	5	4	39	ш		м	3	4	45	36	39	ΙI
	Ni-200	200	300	1700	400	400	400	1100	300	1100			Ar:100	500	400	900	l		A+100	300	400			1800	
	%	100	75	100	100	100	100	100	75	28	681		%	100	100	100	223		%	100	100	100	100	100	376
VI Schr.	a	1	2	3	4	5	6	7	8	9	$\vdash$		q	1	2	3	Н			100	6	9			Н
WISON.	N N	1	1	2	0	1	1	4	1	1			N	1	1	0	ш		Q N	5	1	24	10	9	ΙI
	M	4	4	20	4	4	4	16	4	39			M	5	4	39	ш		M	3	4	45	16	39	ΙI
	Nr-200	100	100	200	0	100	200	400	100	200			Ar:100	100	200	0	ш		A-100	0	200	2400	400	500	ΙI
	%	25	25	10	0	25	25	25	25	2	162		%	20	25	0	45		%	0	25	53	25	23	126
		100	100	200	100	100	200	100	100	200				100	200	100	$\Box$			100	200	100	100	200	
VII Si.	Q	1	2	3	4	5	6	7	8	9			Q	1	2	3			Q	5	6	9	10	12	П
	N	2	2	20	4	4	4	13	3	11			N	5	4	9	ш		N	3	4	32	13	18	ΙI
	м	4	4	20	4	4	4	16	4	39			м	5	4	39	ш		м	3	4	45	16	39	H
	Nr-9200	200	200	2000	400	400	400	1300	300	1100			AH300	500	400	900	ш		A+100	300	400	3200	1300	1800	ΙI
	%	50	50	100	100	100	100	81	75	28	684		%	100	100	23	223		%	100	100	71	81	46	398
		100	100	200	100	100	100	100	100	100		١.	_	100	200	100	ш		_	200	100	100	100	200	Ш
VIII Sta.	Q	1	2	3	4	5	6	7	8	9			Q	1	2	3			Q	5	6	9	10	12	H
	N	1	1	0	0	3	3	4	1	4			N	5	1	9			N	۰	3	34	4	13	H
	м	4	4	20	4	4	4	16	4	39			м	5	4	39			м	3	4	45	16	39	H
	No-2000	100	100	0	0	300	300	400	100	400			Ar:100	500	200	900	l		No-2100	0	300	3400	400	1300	l
	%	25	25	0	0	75	75	25	25	10	260		%	100	25	23	148		%	300	75	75	25	33	208
WY-		100	100	100	100	100	100	100	100	200	$\vdash$		_	100	200	100	$\vdash$			_		100	100	300	Н
Dt Te.	Q N	2	1	3 15	4	1	4	6	2	9 11			Q N	5	5	9			Q N	5	1	9 24	10 6	17	H
	M	4	4	20	4	4	4	16	4	39			M	5	4	39			M	3	4	45	16	39	H
	Ni-200	200	100	1500	0	100	400	600	200	1100			A+100	500	500	900			W-200		100	2400		1700	H
	%	50	25	75	0	25	100	37	50	28	390		%	100	125	23	248		%	0	25	53	37	43	158
		100	100	100	100	100	100	100	100	100				100	200	100				200	100	100	100	200	
X PN.	Q	1	2	3	4	5	6	7	8	9			Q	1	2	3	П	1	Q	5	6	9	10	12	$\Box$
	N	2	2	11	1	3	3	9	3	7			N	4	4	9			N	0	3	25	9	19	
	м	4	4	20	4	4	4	16	4	39			м	5	4	39			м	3	4	45	16	39	
	Nir 200	200	200	1100	100	300	300	900	300	700			AH300	400	400	900			Nr:200	0	300	2500	900	1900	
	%	50	50	55	25	75	75	56	75	17	478		%	80	100	23	203		%	٥	75	55	56	48	234

N: from 39 answers in item 12 where 11 answers relatet to Ps, 9 to Pl and 19 to Ps

TABLE 89: QUESTIONNAIRE PHYSICAL- PSYCHOLOGICAL WELL-BEING, PAIN (WITHOUT ASC)

	physical	%	painless		psychologic	al
			%		%	
AK	437	48,51	198	65,93	298	49,47
EW	335	37,19	223	74,26	265	43,99
HD	658	73,04	178	59,27	407	67,56
KU	638	70,82	178	59,27	491	81,51
NJ	681	75,59	223	74,26	476	79,02
SG	162	17,98	45	14,99	151	25,07
SB	684	75,92	223	74,26	498	82,67
SH	260	28,86	148	49,28	283	46,98
TA	390	43,29	248	82,58	258	42,83
PR	478	53,06	203	67,60	309	51,29

TABLE 90: QUESTIONNAIRE EVALUATION IN COMPARISON WITH INTERVIEW RESULTS (WITHOUT ASC)

ASV	physical		physical x 0,111	painless			painless x 0,333	psycho- logical		psycho- logical x 0,167		physical x 0,111	painless x 0,333	psycho- logical x 0,167	Inter- view x 0,25	Total/ Inter- view/ Pat
1 I AK	437	0,111	48,51	198	0,333	I AJ.	65,93	223	0,166	37,02	I AJ.	48,51	65,93	49,47	73,75	295
2 II EW	335	0,111	37,19	223	0,333	II Ec.	74,26	215	0,166	35,69	II Ec.	37,19	74,26	43,99	15,25	61
3 III HD	658	0,111	73,04	178	0,333	III Ha.	59,27	332	0,166	55,11	III Ha.	73,04	59,27	67,56	61,25	245
4 IV KU	638	0,111	70,82	178	0,333	IV Ki.	59,27	391	0,166	64,91	IV Ki.	70,82	59,27	81,51	62,25	249
S V NJ	681	0,111	75,59	223	0,333	V Ne.	74,26	376	0,166	62,42	V Ne.	75,59	74,26	79,02	87	348
6 VI SG	162	0,111	17,98	45	0,333	VI Schr.	14,99	126	0,166	20,92	VI Schr.	17,98	14,99	25,07	78,25	313
7 VII SE	684	0,111	75,92	223	0,333	VII Si.	74,26	398	0,166	66,07	VII Si.	75,92	74,26	82,67	94,75	379
8 VIII S	260	0,111	28,86	148	0,333	VIII Sta.	49,28	208	0,166	34,53	VIII Sta.	28,86	49,28	46,98	58,75	235
9 IX TA	390	0,111	43,29	248	0,333	IX Te.	82,58	158	0,166	26,23	DX Te.	43,29	82,58	42,83	72,25	289
O X PR	478	0,111	53,06	203	0,333	X Phi.	67,60	234	0,166	38,84	X Phi.	53,06	67,60	51,29	77	308

Figure 10: Questionnaire comparison WITH interviews (-ASC)

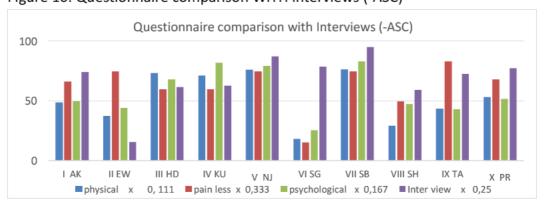


TABLE 91: QUESTIONNAIRE PHYSICAL- PSYCHOLOGICAL WELL-BEING, PAIN (WITH ASC)

	physical	%	painless		psychologic	al
			%		%	
EW2	625	69,4	223	74,3	378	62,7
FG	338	37,5	113	37,6	320	53,1
FHJ	205	22,8	82	27,3	249	41,3
GR	462	51,3	120	40,0	407	67,6
GB	312	34,6	155	51,6	269	44,7
HW	362	40,2	90	30,0	274	45,5
KI	185	20,5	113	37,6	177	29,4
KE	550	61,1	163	54,3	344	57,1
KU2	561	62,3	212	70,6	299	49,6
TH	275	30,5	88	29,3	151	25,1

TABLE 92: QUESTIONNAIRE EVALUATION IN COMPARISON WITH INTERVIEW RESULTS (WITH ASC)

		physical		physical × 0,111	painless			painless x 0,333	psycho- logical		psycho- logical x 0,167		physical x 0,111	painless x 0,333	psycho- logical x 0,167	Intervie w x 0,25	Total/ Inter- view/ Pat
11	XI EW2	625	0,111	69,4	223	0,333	XI (M.5	74,3	303	0,166	50,3	10 (M3	69,4	74,3	50,3	58,25	233
12	XII FG	338	0,111	37,5	113	0,333	XHFG	37,6	270	0,166	44,8	XII FG	37,5	37,6	44,8	91,5	366
13	XIII FHU	205	0,111	22,8	82	0,333	XIII PHU	27,3	174	0,166	28,9	XIII PHII	22,8	27,3	28,9	50,25	201
14	XIV GR	462	0,111	51,3	120	0,333	XIVGR	40,0	307	0,166	51,0	XVGR	51,3	40,0	51,0	82	328
15	XV G8	312	0,111	34,6	155	0,333	XV GB	51,6	244	0,166	40,5	XV GB	34,6	51,6	40,5	46,25	185
16	XVI HW	362	0,111	40,2	90	0,333	XVI HW	30,0	224	0,166	37,2	XVI HW	40,2	30,0	37,2	68,5	274
17	XVII KI	185	0,111	20,5	113	0,333	XVIII	37,6	152	0,166	25,2	XVI KI	20,5	37,6	25,2	36,25	145
18	XVIII KE	550	0,111	61,1	163	0,333	KVII KE	54,3	269	0,166	44,7	NAME	61,1	54,3	44,7	40,5	162
19	XIX KU2	561	0,111	62,3	212	0,333	XX KUZ	70,6	249	0,166	41,3	XIX KUZ	62,3	70,6	41,3	50,75	203
20	XX TH	275	0,111	30,5	88	0,333	XXTH	29,3	101	0,166	16,8	XX TH	30,5	29,3	16,8	54	216
				12,00	6	8,33		12,00		5	20,00					0,25	100000000000000000000000000000000000000

Figure 11: Questionnaire Comparison with interviews (+ASC)

