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## **OLDER ADULT'S EXPERIENCES OF NAVIGATING HEALTHCARE WHILST LIVING WITH MULTIMORBIDITY**

### **Abstract:**

**Objective:** The way older adults navigate their healthcare is critical to supporting positive health outcomes. However, navigating healthcare with multimorbidity is typically disjointed due to complexities in treatment, management, and service provision. This study sought to examine how older patients navigate healthcare whilst living with multimorbidity. **Methods and Measures:** Semi-structured interviews were undertaken with five older adults, aged 65 or older, who are living with multimorbidity in residential care in England. An Interpretive Phenomenological Analysis was undertaken. **Results:** Overall, participants experienced navigating healthcare whilst living with multimorbidity as challenging. Group Experiential Themes included 'Health Knowledge and Understanding', 'Relationships and Expectations' and 'Navigating Health Care with a single lens'. Collectively these themes represented narratives involving how having limited understanding of health conditions, experiencing challenging in communication with health professionals, and receiving segmented care in health care system driven by a single condition focus interfered with navigation. **Conclusion:** These findings highlight experiences of older adults living with multimorbidity navigating healthcare and illustrate several ways older adults living with multimorbidity may be supported to navigate services with less challenges. The research also promotes the need for future research in this area.

## INTRODUCTION

It is estimated that 60% of older adults (over 65 years old), are living with two or more long term health conditions, otherwise known as multimorbidity (NIHR, 2022). The prevalence of multimorbidity increases progressively and precipitously with age and is associated with increased mortality, polypharmacy, and physical decline (Barnett et al., 2012; Marengoni et al., 2011). Vos et al. (2018) highlight that older adults living with multimorbidity find it difficult to orient themselves within the healthcare system, which can negatively influence health outcomes. Vos and colleagues attribute this orientation challenge to healthcare systems being primarily designed for treatment and management of single illnesses and acute conditions with individual departments or units established to manage each condition separately. However, it is not well understood how those with multimorbidity navigate their healthcare in a system that is framed around a 'single disease model' (Luikjns et al., 2016). Individuals with multimorbidity need to identify the right entry point into the system and then find the right type of care, at the right place and right time for their issues (Griese et al., 2020). Understanding navigation processes is fundamental for attempting to reduce fragmented and disjointed care so that patients receive effective and efficient treatment.

To date, research considering how individuals' with multimorbidity experience navigating healthcare is limited. That which exists highlights that communication with and between departments is a central challenge (Vos et al., 2018). Departments do not necessarily communicate with each other, making healthcare navigation disjointed and burdensome (Aggarwal et al., 2020). Additionally, people living with multimorbidity navigate healthcare more frequently and have increased patient-practitioner interactions. These interactions often fail to meet patient expectations leading to losses in motivation and perceived support, creating a barrier to care navigation (Chipidza et al., 2015). Additional research into how older adults navigate their healthcare is therefore necessary, to gain insight into the challenges patients experience that may contribute towards service provision and development.

The concept of 'Health Literacy' is an important consideration in the study of healthcare navigation. Health literacy is defined as the individual's ability to obtain and translate knowledge and information to maintain and improve their health in a

way that is appropriate to them (Liu et al., 2020). Health literacy is widely recognised as a critical skill that enables and helps people to become active agents in their own health care (Jacobs et al., 2017). Patients must learn about and process knowledge about their complex health needs to effectively manage their health (N'Goran et al., 2018). For patients with multimorbidity, additional literacy is required with each condition and how they overlap. For older adults living with multimorbidity this is more likely to present a challenge. Older adults are more at risk of poor health literacy owing to a variety of psychosocial factors such as socioeconomic status, cognitive decline, and other age-related changes (Chesser et al., 2016). However, the experiences of patients with multimorbidity using their health literacy skills to aid their navigation of healthcare are not well documented. This presents an important topic for investigation with health literacy being seen as a critical topic in public health (NHS, 2021).

The implications of fragmented, incomplete care to both the healthcare system and the individual are well documented (NIHR, 2022). The navigation of healthcare for individuals with multimorbidity is a critical aspect of effective and efficient healthcare (Boye, 2019) and it is important to develop our understanding of this topic. In particular, older adults with multimorbidity and their experiences navigating healthcare is of interest as this group represents a growing portion of the population that has previously been underserved in literature (Petrovsky et al., 2022). Understanding how older adults navigate their healthcare with multimorbidity will provide insight for service providers to reflect on the ways services are delivered and promote quality of care (Jackson et al., 2012). The value of patients' experiential knowledge and expertise in healthcare, is increasingly recognised by policy makers, service providers and researchers in providing new angles and perspectives to address current issues and challenges. Considering this, the current study sought to explore experiences navigating healthcare for older adults who are living with multimorbidity.

## **METHODOLOGY**

### **DESIGN**

A qualitative study using individual semi-structured interviews was conducted to gain insight into older adults' experiences of navigating healthcare whilst living with multimorbidity. To enable this insight into individuals' experiences, it was grounded in a phenomenological ontology (Smith et al., 2022). This assumes that reality is a production of human experiences, and therefore, individuals are creators of their own reality. Whilst all individuals are influenced by others, all experiences are different (Smith et al, 2022). As phenomenology is the study of human experience, Interpretative Phenomenology Analysis (IPA) was an appropriate fit for this study.

The adopted epistemological position was critical realist, a position that assumes there is no universal truth. Instead, individuals have a widely accepted understanding of the world which is dynamic and continuously evolving. Reality is socially embedded, existing in the mind of the individual, and knowledge is developed through our own processes and experiences (Cuthbertson et al, 2019). IPA is theoretically rooted in critical realism (Fade, 2004). Furthermore, the phenomenological requirement within IPA is to understand and 'give voice' to individuals, with the interpretive element contextualising and making sense of this from a psychological perspective (Larkin et al, 2006). Therefore, the ontological and epistemological positions were suited to enable exploration and insight into individuals' unique experiences in this study.

### **Procedure**

Upon institutional ethical approval, the study was advertised in retirement villages via promotional posters and leaflets delivered to residents, which outlined the inclusion / exclusion criteria. This setting was chosen due to the accessibility and availability of older adults (aged 65+), with between 170 and 350 residents living in each retirement village. Given that 60% of older adults live with MHC's (NIHR, 2018), it was assumed suitable participants could be identified in this setting. As this study was interested in the experiences of multimorbidity without prescribed conditions, and due to the nature of the setting, a volunteering recruitment process was deemed most suitable for this study.

Those who volunteered were provided with an information sheet outlining the details of the research. Once written consent had been gained, semi-structured interviews were conducted, and audio recorded by the lead researcher. Interviews lasted between 60 and 90 minutes. Interviews were carried out on-site at the retirement village, in individuals' homes or in private rooms. This allowed for the immersion of the lead researcher into the participants' world, whilst also utilising a space that individuals are comfortable with.

Rapport was established early on in interview process, by the lead researcher showing interest, support and understanding (Kahn & Cannell, 1957). This was further built upon through responding empathetically and developing coordination; facilitating smooth question and answer sequences throughout the interview.

Participants were encouraged to talk openly about their experiences through a semi structured approach, allowing the interviews to be guided by their experiences, exploring the elements which were important to them (Coolican, 2024). The interview schedule included eight open questions designed to explore participants experiences of navigating health care including accessing healthcare services. Example questions and prompts included paths used to engage with healthcare and their most recent experience. All questions were framed in the context of multimorbidity to ensure this phenomenon remained central in the research.

The interview schedule was initially developed in the design phase of the research but was assessed for its ability to draw out a response to the research question during two pilot interviews. As a result, the interview schedule was adjusted and refined during this process. The interview schedule was then used as a prompt throughout the interview (Smith, 2015). The pilot interviews also allowed the researcher to develop an effective interview style / approach (Smith et al, 2022).

Following the interview, participants were presented with a debrief form and the researcher conducted a wellbeing check with signposting / support resources offered as required. Upon conclusion of the interview, they were transcribed verbatim. Participants were invited to check their transcript for accuracy, however, no participant requested to do so.

## **Participants**

Five participants (4 female, 1 male; average age: 84) volunteered their participation from two retirement villages located in the Southwest of England. Inclusion criteria was being over 65 years old and living with two or more long term health conditions. Individuals with known cognitive impairments (e.g. dementia) were not included in this research.

Overall, participants had a diagnosis of between four and eight long-term health conditions that included heart disease, chronic pain, cancer, and depression. An overview of participants can be seen in Table 1.

## **Data Analysis**

To undertake the analysis, Smith et al.'s (2022), seven-stage analytical approach was followed. Analysis was primarily undertaken by the lead researcher (HG) and started with data familiarisation, becoming immersed in the data, and was followed by line-by-line exploratory notations of semantic content and language (Larkin et al., 2006). Next, experiential statements, grounded in the data, yet abstract enough to be conceptual (Smith et al., 2022) were used to help to consolidate and crystallise developing thoughts. These experiential statements were then organised and explored through a scattering and clustering process whereby patterns of constructed experiential statements were mapped to show their interconnections which led to the development of participants' Personal Experiential Themes (PETs). PETs were organised into tables and subsequently named. In some instances, sub-themes emerged and were captured accordingly. This stage produced a level of organisation, reflecting an analytic entity present within the transcript as a whole, as opposed to being tied to specific and local instances within the transcript. This process was repeated for each individual transcript. In the final step, working with each participant's PETs, Group Experiential Themes (GETs) were developed across the cases. The GETs were named and represented into one central table (Figure 1). At each stage of analysis, the second researcher (MS) reviewed progress and interpretations, and acting as a 'critical friend', challenged and requested justification of the analytical process.

## **Positionality and reflexivity**

Both researchers were aged 35-40 at the time of undertaking the research operating within a UK university. The research was initially developed through the lead researchers' lens of professional experience working with older adults, many of whom live with multimorbidity. Consequently, with a subjective view on this topic, reflexivity was embraced throughout the entire research process. Transparency of the relationship between participants, the topic, and researcher aid critical understanding and supporting validity of the analysis (Dodgson, 2019). Subjectivity was managed through the second researcher reviewing the transcripts and the lead researchers' interpretations of them, challenging interpretations and maintaining a critically reflexive dialogue throughout the analytical process. To support this dialogue and to achieve bracketing, the lead researcher kept a reflexive journal which included, thoughts, feelings and assumptions to encourage the analysis to be constantly questioned (Hale et al, 2007).

Finally, but not exclusively, adopting and maintaining the epistemological and ontological positions encouraged the lead researcher to ensure individuals were at the centre of each stage of the research, consciously recognising individual realities exist in the mind of the individual and are developed through their own processes and experiences (Cuthbertson et al, 2019).

## **FINDINGS**

Three GETs were interpreted from the participants' experiences of navigating healthcare (see Figure 1). These included 'Navigating healthcare with a single lens' 'Health knowledge and understanding,' and 'Relationships and expectations.' Each GET will be discussed in turn, alongside direct quotations. See Table 2 for participant endorsement from the qualitative data.

### **Navigating healthcare with a single lens**

Participants described their experiences of navigating healthcare with multimorbidity as being typically centred on one main condition. Whilst all participants live with multiple health conditions, experiences of navigating healthcare were framed through the lens of a particular condition / diagnosis. For example, despite the recognition that other conditions impact her, Barbara's experiences were centred on "*the main thing*" being chronic pain.

*“I have polymyalgia rheumatica...I have severe scoliosis, um, and degenerative disease of the spine, osteoporosis... that are the main issues of pain. I have ongoing heart issues, continued high blood pressure. I have pancreatitis. I have Raynaud's disease... I have multiple pressures; my stomach has compressed my liver and part of my pancreas has died back... but the pain is the main thing”*

It is this condition which forms the basis of how she subsequently reflects and explores her experiences of navigating healthcare throughout the interview. The impact of taking a single lens is clearly reflected in participants experiences, such as by Freya here; *“I don't stop to consider what health conditions I have”* and is indicative of attempts to cope with the management of their healthcare. Individuals navigate through healthcare focusing on the conditions which are causing the most impact to them at a given time. What is considered impacting, is multi-dimensional, spanning current symptoms experienced, limitations on daily activities and even treatment burden related to the symptom affecting the individual the most. These may contribute to the way an individual determines their *“main”* condition. Notably, the impact of an individual's health conditions is articulated across all participants and reflected within the analysis, in the PETs labelled ‘the importance of treatment,’ the ‘impact of living with MHCs,’ and ‘coping with conditions’.

Throughout participants' experiences, they draw on a sense of navigating healthcare as their right to engage with healthcare services about their own health (*“I ought to know what's going on”*), their choice (*“I said no, it's my decision”*) and effectively determined by them (*“It is at my request”*), reflected here by Barbara and Denero. These comments suggest that despite living with multiple health conditions, a sense of control is realised when individuals engage with healthcare on a condition by condition, symptom by symptom basis. Despite the presented challenges of living with multimorbidity, this sense of control over one condition becomes a strategy to cope with living with multiple conditions. A singular lens approach to accessing, navigating, managing, and viewing their health, may therefore reflect a coping strategy centred on providing individuals with a sense of control over their conditions as suggested by Freya *“I don't stop to consider what health conditions I have.”* Not stopping to consider multiple conditions may reflect this coping response by which

Freya navigates her healthcare through the problems which are causing the most impact to her at a given time, to avoid becoming overwhelmed.

Navigating healthcare through a single lens may not always be driven by the individual. At times, this is explicitly and implicitly facilitated and endorsed by the healthcare system, reflected in the quote below from Diana:

*“I don’t really get support [for living with multiple conditions], I just, if I’ve got something wrong with me, I go to the doctor.”*

It is implicitly expressed that they are encouraged to access healthcare when they have “*got something wrong*” i they will receive support through the singular conditions or symptoms that they present with. Healthcare creates a perpetual cycle here where patients are seen to be supported only through singular conditions, in isolation of others, thereby giving them no alternative other than to continue accessing healthcare with a singular lens.

Some participants were able to reflect on how taking a singular lens was divergent from a holistic perspective, for example “*If I’ve got all these multiple health things, why aren’t they checked out?*.” Here, Valerie questions why her health conditions are not considered holistically, yet paradoxically and inexplicitly discusses throughout the interview how she navigates her healthcare through a “*main*” condition. Individuals simply access healthcare services based on single conditions/symptoms, as and when they are experiencing “*something wrong*.” Further reflected here by Diana; “*If I have a problem, I go to the doctor.*” Diana further reflects on some of the challenges faced when attempting to receive treatment for multiple health conditions;

*“That’s a different department but they will liaise between them, which is good because a lot don’t”.*

Diana observes how seeing different departments for different conditions requires effective organisational communication which is often not experienced and leads to frustration; “*the most difficult thing is getting them (health conditions) all together to get them linked.*”

## **Health knowledge and understanding**

Throughout the interviews, participants explore navigating healthcare by drawing on experiences that demonstrate a backwards and forwards motion (tug of war) that represents a conflict between dependency and independence with healthcare. This conflict was underpinned by participants' health knowledge and understanding and made up by the following PETs, 'limited understanding,' 'shared knowledge.'

### *Limited understanding*

Participants explored different ways limitations in their knowledge and understanding of their health conditions impacted their healthcare navigation. Specifically, the ways in which limitations in knowledge creates and reinforces barriers to navigating healthcare. For example, Denero explains how information relating to his cardiac condition was given at the time of health crisis or illness diagnosis, but knowledge on what to expect along the illness trajectory was not shared. Knowledge was effectively restricted and limited;

*“But what to expect...later on in cardiology terms was never explained and still hasn't been. It's the intricacies what's missing”*

Valery shares a similar experience:

*“I have not received information from them (health professionals), about my heart, never, nothing. For years and years and years”.*

Limited information or knowledge, specific to the individual, creates a conflict of having to depend on healthcare services whilst wanting to manage their healthcare independently. This conflict creates confusion, frustration, and anger with navigating healthcare and participants collectively discussed experiencing a loss of control. For example, Valerie details her frustration of trying to speak to a health professional about her symptoms and they not being forthcoming with information or readily available;

*“[they said they would be in touch] But that never happened. And that went on and on and on. And in here, I've got phones saying, I'm sorry, he can't speak to you. I'm sorry, he can't. And in the end, it [they] said he couldn't speak to me, there's a date in there. It [they] said that he could speak to me, and when he spoke to me, I said all the things...and he said, well, okay, let's do a*

*sputum test. Then they did the sputum test, and I did have a bloody chest infection”*

Here, Valerie tries to make sense of an experience navigating the doctor’s surgery but with limited knowledge of the condition itself and of what should and shouldn’t happen, she is grappling with not feeling supported, not knowing what is going on or what indeed she should be doing.

Other reactions to having limited knowledge were stoicism and helplessness, with participants noting that they simply need to *“get used to it”* (Denero) or *“you soldier on you know”* (Freya). These reactions illustrated that participants had developed coping resources to manage their health conditions and having to navigate healthcare, *“you learn to live with it”* (Barbara). Similarly, being left to *“get on it with it”* (Diana) led to individuals feeling they had been deserted, finding themselves in a position where navigating healthcare becomes a case of *“helping yourself or get no help”* (Denero). It suggests, because of limited knowledge to effectively navigate healthcare, individuals’ self-efficacy is impacted, thus reducing motivation, leading to reduced or limited help seeking behaviours.

A lack of understanding impaired participants knowing when to access and how one might need to navigate their healthcare across the illness trajectory. For example Diane outlines how, she has not received any information regarding her conditions, and as a result she accesses healthcare services when she thinks there is *“something wrong”*. This way of navigating healthcare may lead to an increase in unnecessary engagement engaging with services, or equally a disengagement, feeling *“just left to get on with it”* and having no choice but to manage their conditions independently.

Barbara recalls a time prior to when the ‘NHS’ was established, where knowledge and understanding of health conditions, as well as a system where health conditions could be discussed and treated, did not exist in the way it does now. This is also explored by Freya, who spoke of a time where ‘knowledge’ in the way it is known now, unknown at an earlier stage of her life, *“I’m 93, and when I was young, there wasn’t any sultan screening notion”*. Participants have learnt through navigating healthcare services for over 70 years to manage their multimorbidity by learning to *“get by”* without knowledge and understanding.

Overall having a limited understanding of their health conditions coupled with a long history of navigating healthcare through a changing health service is reflected in participants experiences. For older adults who have learnt to expect and depend on healthcare services to provide knowledge, and access healthcare when there is “*something wrong*”, attempting to unpick how this might be managed to improve patient care requires careful consideration. One option might be the creation of ‘shared knowledge’.

### *Shared Knowledge*

Participants discussed the idea of shared knowledge shaping the way in which they can navigate their healthcare more effectively. For example, Diana compares two different experiences with consultants and how one attempted to develop and share knowledge whilst the other did not;

*“I know that the um the doctor that I, I see In a hospital, the specialist, she um, she's amazing...and the next time um, I saw her and...when I received the, the notes from her, she'd written a whole page of questions and answer, and things for me to think about and it makes such a difference... whereas the, the gentleman, didn't give me an opportunity to ask questions or to, to say anything, really. And, and yet she did. She, she, we had a proper conversation, I could ask her anything”*

In this example, the health care professional challenged the Diana to consider her health conditions and create shared knowledge. She predominantly leans on the experience where the professional took an active role in attempting to develop their own knowledge of Diana, “*she'd written a whole page of questions and answers*”, as well as Diana’s knowledge, “*things for me to think about*”. She compares this to a previous experience, implicitly indicating the opposite happened with the previous healthcare professional (HCP), referred to here as “*the gentleman*”. This experience motivated and empowered Diana to reflect on her health, whilst encouraging her to develop help-seeking behaviours in the context of her existing health knowledge.

Participants explored the way in which they discuss and share their own knowledge, with that of the healthcare professionals. Through this exchange of knowledge and information, ‘shared knowledge’ is developed, which enables better perceived health decision making as Barbara explains;

*“I talk to him, I talk to him in great depth. He wanted to increase this particular tablet um, to a much higher level, much, much higher level. And I said, well I'm not prepared to do that. I said, um, can it be increased gradually... So my first lot of the morning is 12, 13 different tablets. Within an hour, I'm spaced out. I said can that one tablet, go to a later time, where I'm only taking six or eight? I haven't got so much going on. We discussed it, he came back to me. He said that will be fine.”*

A joint or ‘co-produced’ approach to knowledge production contributes to both professional and patient reaching a conclusion and strategy for treatment. Navigating healthcare therefore becomes a process of collaboration, with shared responsibilities, where patients feel supported and maintain a sense of autonomy.

Participants experiences highlight the importance of patient-practitioner relationships in the navigation of health care. Effective communication between the patient-practitioner acts as the vehicle in developing shared knowledge. Having a shared knowledge reflects having a more effective and positive experience, where there is less of an *“uphill battle”* (Barbara) to accessing, engaging, and navigating healthcare. It reduces conflict between professionals and patients shaping how healthcare is navigated currently and how it will be approached in the future. Participants indicated that creating shared knowledge increases their motivation towards their healthcare; *“I don't have to go; I want to go”* reflects Freya. However, experiencing a sensation of creating shared knowledge was discussed as happening infrequently, as Diana exclaims; *“I must admit, I have never had that before”*.

The development of shared knowledge between the healthcare provider and the patient, in the navigation of healthcare with multimorbidity is seen as a critical component in positively shaping and influencing participants experiences. It empowers individuals, reflected by Valerie *“It is your right to know what you've got, what they're doing and why they are doing it,”* improving their self-efficacy, whilst promoting knowledge help seeking behaviours for their complex multimorbidity, explored in the below quote from Diana;

*“Now I do question it. I do ask why. Why are you doing this? What have I got to take that? What will that do? What will happen if I do not do it?”*

## Relationships & expectations

This theme considers the role of other people in facilitating or thwarting effective navigation of healthcare services. Participants explored this in several ways as evidenced in the sub themes, which at times, became blurred and conflicting. For example, participants often placed great expectations on important others and health professionals for directing, leading, supporting and taking responsibility for their healthcare navigation. However, this contrasted with participants feeling that navigating healthcare was their own responsibility and wanting to be independent of others or professionals.

### *Important others*

Participants spoke of family, close friends and personal carers being important in supporting them to navigate healthcare services. This was often an enabling influence and provided practical support such as taking them to and co-attending appointments, handling interactions, as well as drawing on their own knowledge of healthcare, articulated here by Barbara *“Getting to hospital, I have to have my carer come with me as well”* and here by Diana *“And he [neighbour] took me to hospital”*. Additionally, when considering how to holistically manage their healthcare, Denero acknowledged the role of important others; *“And so to try and manage better yourself with these conditions, get some family and friends to help”*.

However, sometimes it was seen as a disabler to healthcare navigation in that it reduced help seeking behaviours and increased a sense of reliance on important others. For example, Valerie explains how their daughter takes care of everything associated with their healthcare, *“I have always relied on [my daughter] to help me with doctors and that, because she was always there...and I haven’t felt able to do it.”* A combination of age and the multiples of health conditions appeared to further impede help seeking behaviours *“The thought of me saying phone up the doctor and talk to him. That’s ever such a big, big thing to me. Where it wasn’t, like, years ago.”* despite there being a desire for independence with navigating healthcare *“I can’t go and do any of the things..I am hoping to do it all myself again”*.

### *Professionals*

Participants expressed strong ideas of what they see as the professional's role and associated expectations within their healthcare service provision; *"I'm sure that doing their best but uh, it's still not good enough for the patient"*.

Participants underlined the importance of the patient-practitioner relationship, discussing how communication, interpersonal skills and the development of the relationship impacted their navigation and engagement with healthcare. Participants specifically spoke of feeling that their thoughts and experiences were dismissed by healthcare services which was both insulting and hard to accept, as articulated by Barbara *"It has been very very difficult...people are dismissing me"*.

Unfortunately, it has become something they feel they have to manage themselves which has led to gradual disengagement from healthcare services; *"you want to do something about it, and you can't. So uh, you just have to do the best you can"*.

Additionally, perceived difficulties of not seeing the same doctor / healthcare professional; *"But every doctor I saw was a different one, which was, was a bit tricky"* and melancholic reflections on the changes between how doctors used to be and how they are now were also reflected; *"the doctors aren't the same as they used to be"*.

These difficulties became cumbersome as individuals navigated their health, as with a complex health status they felt they had to *"start from scratch"* each time they engaged with healthcare professionals. Participants felt that these issues navigating healthcare services had worsened over time and that previous doctor-patient relationships were more personalised, where the doctor really knew you, reflected by Diana below:

*"It's less personal than it used to be. If you had a GP, you always had that GP, and now, I mean, we are quite lucky in that we have got a small practice, but I know quite a lot of people go and they never know what doctor they're going to see."*

## **Discussion**

The current research explored experiences of navigating healthcare for older adults living with multimorbidity. Findings indicate that several common threads wove

through participants' experiences that serves to expand and broaden existing knowledge in an under-represented area. The current research contributes to existing calls (e.g. Funk, 2019) for a shift away from the single-disease model of patient management towards something more holistic and collaborative between patient and practitioner. Findings illustrate some of the challenges that accompany older people as they navigate their healthcare with multimorbidity which is necessary in the development of patient-led, person-centred approaches to healthcare (NIHR, 2022).

The way that participants discussed navigating their healthcare with a single lens reflects the 'single disease' or 'main effect model' underpinning health care provision in the UK, that dictates healthcare should be navigated through approaching conditions individually (Chipperfield & Greenslate, 2013; NIHR, 2022). This single lens approach disregards the concept of multimorbidity, despite the psychological and functional interaction that occurs between health conditions (Lee et al., 2020) and any potential impact to an individual's quality of life (Megari, 2013). The adoption of the single lens mindset may act as a coping resource, providing participants with a sense of control over their health. Literature has highlighted that age and multimorbidity are strongly related to reduced mastery and control beliefs (Rijken, 2020). Grappling with the overwhelming effects of aging with multiple health conditions, individuals perceive themselves as having greater control over their conditions when navigating healthcare with a singular lens. The notion of choice in the adoption of a 'single lens' approach as a coping resource is a fallacy, with patients having no other approach available to them. The experiences of participants feeling they have no other way of accessing healthcare than through a single lens approach extends previous qualitative research in this area (e.g. Vos et al., 2018). It extends it by identifying that this feeling is perpetuated by healthcare professionals, directly and indirectly, raising a continuation from the theme 'roles and relationships' that patient-practitioner relationships are central to effective health care experiences and outcomes (Drossman & Ruddy, 2020). However, in contrast, health professionals are encouraged to be patient-centred, and therefore breaking this cycle of behaviour and dependency, may be difficult. Indeed, research has highlighted how organisational pressures regarding throughput impact health professionals' ability to develop and sustain patient empowerment and relational care

(Mc Namara et al., 2017). In Mc Namara et al.'s study of health professional perspectives on the management of multimorbidity and polypharmacy for older patients in Australia, many health professionals were reluctant to take responsibility for enacting a patient-centred approach when the organisational structure and culture did not support this. Further research should consider the experiences of healthcare professionals in supporting patients with multimorbidity, building a more rounded understanding that considers the instrumental and critical perspectives of both patient and practitioner.

The conflict between multimorbidity and the 'single-disease-model' poses significant challenges for effective healthcare navigation and the management of conditions (Albert, 2012). Alternative approaches to healthcare practice might negate some navigational challenges such as the adoption of more holistic healthcare practices and the increased use of Advanced Practice Nurses or Nurse Practitioners (International Council of Nursing, Nurse practitioner/advanced practice network, 2016). Indeed, Eriksson et al. (2018) identified that Nurse Practitioners increased patients' accessibility to health care and were perceived as providing holistic, continued care that was appreciative of multimorbidity. However, further research is needed investigating how the challenges of healthcare navigation with multimorbidity can be managed, as well as the efficacy of holistic healthcare practices.

Knowledge and understanding are important to participants as they manage their multiple health conditions and navigate healthcare. Long term health conditions are dynamic in nature, developing and changing over time and requiring a complex level of understanding to effectively manage (Sturmberg, 2021). Having limited personal knowledge and understanding is likely to impair self-efficacy towards healthcare, further impairing motivation and help seeking behaviours (Teo et al., 2021). Knowledge allows people to better understand themselves and their capabilities, promoting a sense of autonomy and mastery over a particular situation, which is important in the development of self-efficacy. Self-efficacy is an antecedent and outcome of health literacy (Lee & Oh, 2020). In alignment with participants experiences, poor health literacy is a known barrier to participation in healthcare (Berkman et al., 2011), affecting motivation, autonomy and help seeking behaviours (Protheroe et al., 2009). Existing research posits that individuals living with multimorbidity typically have lower levels of health literacy (Amaral et al., 2022) and

within the current study, participants' experiences of navigating healthcare were clearly shaped by their limited knowledge of their conditions and the care available to them. This limited knowledge (a core component of health literacy), appears to create barriers accessing, engagement and navigation of healthcare.

The process of developing 'shared knowledge' was presented in the current research as positively shaping the way participants navigate healthcare effectively. This was through perceived sharing of responsibilities, promoting individuals to feel supported, whilst maintaining autonomy and self-efficacy (Warner et al., 2011). This is more likely to lead to improved treatment adherence, polypharmacy, as well as a reduction in the frequency in which individuals engage needlessly with the healthcare service (Berkman et al., 2011). Establishing a shared knowledge can be understood in respect to the fostering of shared decision making (Gulbrandsen, 2020). Decision making in healthcare is a complex and critical issue for older adults with multiple health needs (Coulter & Collins, 2011). It is further complicated by reduced availability of coping resources, increased polypharmacy, and the limited availability of support networks (Leppin et al., 2015). Sharing this decision-making process is a way of positively influencing individuals' experiences, motivating them to engage in positive health behaviours. However, owing to the way health literacy is commonly operationalised as knowledge being 'given' to individuals to enable them to self-manage their conditions independently (Bodenheimer, 2002), collaboration is often illusive in healthcare practice (Brand & Timmons, 2021). In line with the theory of knowledge sharing (Carlisle, 2005), experiencing the co-production of knowledge and understanding appeared to empower individuals, affecting their sense of control and motivation in the navigation of their healthcare. Co-production builds on individuals' capabilities and promotes a reciprocal patient-practitioner relationship, focused around facilitating healthcare with patients rather than delivering healthcare to patients. Patient empowerment is a long-term ambition of the NHS and is recognised as encompassing education or health literacy (NHS, 2019). Developing knowledge and understanding through co-production presents an alternative way of developing patient knowledge, promoting a culture of continuous learning and with it, a cyclical enforcement of empowerment and an internal locus of control to effectively manage their health. This approach to navigating healthcare also provides healthcare benefits in understanding and treating the whole person (Haslam, 2015).

The theme 'Relationships and Expectations' aligns neatly with existing literature regarding the importance of social support and effective patient-professional relationships in healthcare (Drossman & Ruddy, 2020). For example, participants' descriptions of close, familial relationships being invaluable sources of emotional, informational, and instrumental support, enabling the navigation of healthcare have been previously documented (e.g. Gage-Bouchard 2017). However, this seems to challenge the healthcare agenda of empowering individuals to take control of their healthcare, by playing an active role in shaping it. It is therefore interesting the finding that supportive relationships can sometimes thwart patients' navigation of healthcare through increased reliance and a reduction in self-efficacy. This may be understood with reference to received social support visibility (Uchino, 2009; Zee & Bolger, 2019). The receipt of direct (visible) support that is interpreted as help by recipients is more likely to lead to negative outcomes, specifically a drop in self-esteem or threat to independence (Bolger & Amarel, 2007; Uchino, 2009). Zee and Bolger (2019) suggest that *invisible support* (providing support unbeknownst to the recipient, often before it is requested) may be more effective in supporting individuals through stressful events. This raises an important implication for how patients are guided and supported through their care and whether important others should consider the visibility of their support.

Patient-practitioners' relationships were commonly cited and recognised as central to health outcomes and experiences (Chipidza et al., 2015). Effective communication and continuity of care are fundamental to a patient-centred approach (Drossman & Ruddy, 2020). Patient's feeling that their thoughts are often dismissed is sure to lead to disengagement and resentment towards healthcare providers. This is something which has been documented elsewhere (e.g. Noseworthy, 2019; Otte, 2022) and posits an important area for improvement within healthcare provision.

Study limitations include methodologically, retrospective interviews may be considered limited in their capacity to capture the experiential nuances of this topic. It is likely that participants were unable to recall or adequately vocalise their experiences limiting conclusions drawn. Future research should consider the utilisation of other qualitative approaches, such as daily diaries, that provide alternative perspectives on this topic. Additionally, whilst not a disadvantage of the research, participants did not necessarily reflect the multicultural landscape of the

UK, and which are likely to hold diverse experiences of healthcare navigation whilst living with multimorbidity. Additionally, participants were recruited from a small geographical area. There is continued evidence (spotlighted by the COVID-19 epidemic) that ethnic minority groups tend to receive lower quality of care, with greater morbidity and mortality risks (Tai et al., 2021; Yaya et al., 2020). Therefore, future research should prioritise attempting to capture the experiences of a diverse population, particularly those likely to suffer from marginalisation and inequality. Furthermore, additional interpretations based on non-verbal language, as well as the choice and delivery of the language was beyond the scope of this research. Further research should attend to these considerations as it may provide further insight into these experiences.

In summary, the experiences of navigating healthcare of older people living with multimorbidity were represented in three themes which included, 'Navigating healthcare with a single lens' 'Health knowledge and understanding,' and 'Relationships and expectations'. Principally, navigating healthcare whilst living with multimorbidity was not experienced in a positive manner, with the way in which the single system impairs navigation being of particular importance. This research has primarily highlighted aspects for further research, namely, to develop understanding of health literacy for older people living with multimorbidity, with a particular emphasis on experiences of individuals from diverse backgrounds. Greater knowledge in this area can help to bridge the gap in understanding and improve navigation of healthcare, leading to improved quality of life and health outcomes. Furthermore, with higher medical costs, longer average hospital times, and increased frequency of healthcare services associated with multimorbidity (NIHR, 2022), improving healthcare navigation may address these challenges going forward.

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## Tables and Figures

**Table 1 – Characteristics of individual participants**

<i>Pseudonym</i>	<i>Gender</i>	<i>Age</i>	<i>Number of conditions (self-reported by participants)</i>
<i>Barbara</i>	Female	88	8
<i>Denero</i>	Male	69	6
<i>Diana</i>	Female	83	5
<i>Freya</i>	Female	94	4
<i>Valerie</i>	Female	91	4

**Figure 1 – An overview of the organisation and makeup of the Group Experiential Themes interpreted from the participants’ experiences of navigating healthcare.**

<b>Group Experiential Themes (GETs)</b>	<b>Sub-Themes</b>	<b>Example Participant Experiential Themes (PETs)</b>	<b>Example Experiential Statements</b>
Health Knowledge & Understanding	Limited knowledge	Knowledge impacts navigation of care	The length of time living with the conditions increases the known information but not accessibility
		The interplay of knowledge and understanding of health with navigating health care	Understanding of health / illness has changed over time
	Shared knowledge	The role of stage of life in shaping health understandings	Reflection on health trajectory which may have changed if “cures” available at a younger age
The nature of the patient - practitioner relationship seen as importance in navigation of health care		The approach with doctor / patient communication seen as important in navigating health care	
Relationships and Expectations	Professionals	What positive experiences look like	Relationships forged with nurses where they know you, positively shapes experiences
		Navigation of health care requires understanding and knowledge of health	Mutual understanding of ability to handle conditions.
		The role of health care professionals in navigating health care	Professionals create opportunities to improve the quality of life

	The role of professionals in shaping experience	Taking responsibility over individual health depends on the professionals helping
	The role of treatment underpins understanding of health	"Professional" engagement with treatment motivates action
Important others	Accessibility	Neighbourly / community support facilitates access to healthcare services
	Knowledge of health care affects navigating and management of conditions	Familial knowledge of healthcare facilitates accessibility and reduced individual responsibility
	The role of others in supporting accessibility	Reliance and dependency on others to support health care access
Navigating Healthcare with a single lens	Individuals are directed to main conditions rather than multiple conditions	Reflection of conditions are directed to one main condition
	Knowledge effects the navigation of care	Individuals do not view their health as multiple health conditions, but instead are led by a main condition
	Conflict of responsibilities in navigating health care	Dynamic nature of long-term health conditions relies on active engagement