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# Report of a literature review on disease education for People with Parkinson's



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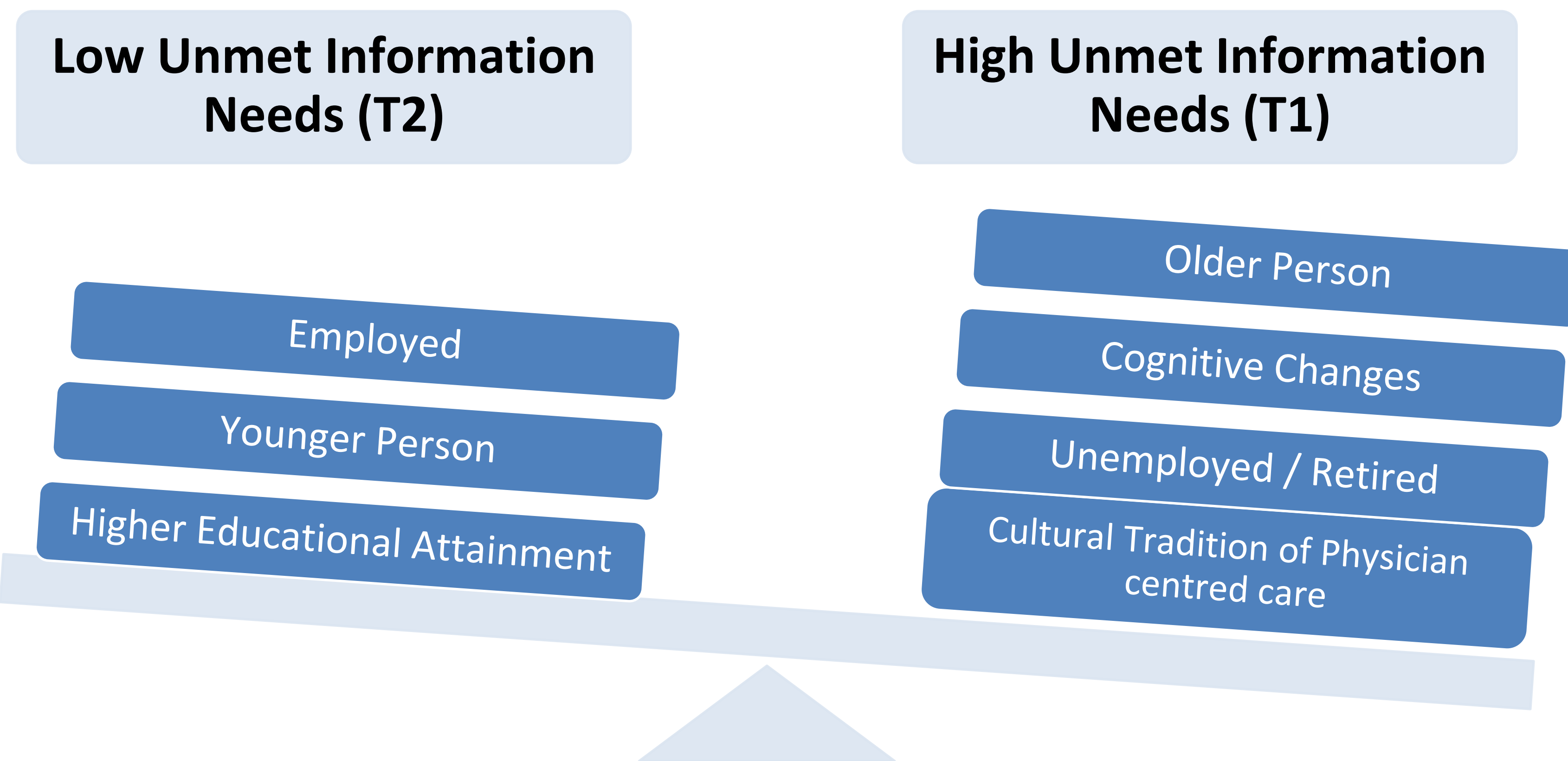
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## Purpose

Disease-specific research on the information needs of people with Parkinson's is non-existent but other diseases with a similar impact have been studied. This area of knowledge has a direct impact upon self-management of diseases as well as on quality of life. While Parkinson's is not a life-threatening disease in the usual meaning of the words, it results in significant, increasing disability and receiving the diagnosis is a life-altering moment. The person may experience conflicting sentiments of relief and turmoil, described by some as “life-shattering” (Pinder, 1992).



**Figure 1: Attributes of patients with high and low unmet information needs**

## Methods

Google Scholar, Cochrane and PubMed were searched to identify randomised controlled trials, evidence-based review articles and meta-analyses, as well as evidence-based guidelines. Only articles in English were studied.

The search included articles published between January 1990 and February 2012 using the keywords and subjects: “Parkinson’s”, “information needs”, “patients”, “carers”, and “diagnosis”. Two review articles (Adams, Boulton and Watson, 2009; Kinnersley et al., 2008) and twenty studies (Wherry, 2012) were found and analysed.

## Findings

Two types of patients were noted within the literature. Type one (T1) was older, possibly had mild cognitive changes, had a lower level of educational attainment, and was likely to be retired or unemployed. Type two (T2), was younger, had a higher level of educational attainment and was likely to be still in employment (Kim et al., 2012). The typical T1 patient had a higher level of unmet information needs than T2 patients who were proactive in seeking information. Complex and rarely asked questions were more likely to be presented by T2 patients. These findings are shown in figure 1.

Preferred sources of information for T1 patients included physicians and specialist nurses, whereas T2 patients supplemented the information from their care team by using external sources (Andreassen et al., 2005). Cultural behaviour in health had an impact, some patients exhibiting a higher reliance on medical teams for information and decision making than others (Wittman et al., 2011).

Information needs changed over time and there was an obvious challenge to identify these needs when the patient was seen in a clinic setting (Kim et al., 2012). The level of information provided influenced help-seeking behaviour and a balance between inappropriate reassurance and overemphasis on complications was necessary (Wittman et al., 2011).

## Discussion

Chronic care health professionals have begun to see patients from the Baby Boomer generation and can anticipate a rise in “technologically-savvy” T2 patients who demand high levels of communication and consultation with their care teams. The challenge remains to identify the specific information requirements and so meet patients’ needs in a personalised manner.

In the light of this literature review, local practice has evolved to institute a nurse-led clinic and to provide patients with an information pack, specifically focused on the needs of newly-diagnosed patients. Given the prevalence and impact of Parkinson’s, the research base in this area is currently insufficient to inform policy and practice. Future research should explore the changes in information needs over the course of the disease, including the needs of the primary carers. A study identifying the best way to meet these needs is urgently required in order to ensure that best practice is informed by relevant and robust evidence.

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**Figure 2: Preferred sources of information**  
(Blue: T2. Purple: both T1 & T2)