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# Patients' Perceptions on Effects of Parkinson's Disease on Quality of Life

A Descriptive Literature Review

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| <p>The purpose of this thesis was to describe patients' perceptions on effects of Parkinson's disease on their quality of life. The aim is to produce knowledge on how Parkinson's disease affects the patients' quality of life in order to develop the care directed to this group. The effects of Parkinson's disease on quality of life can be categorised into physical, psychological and social effects. These effects are often interlinked with each other and contribute to the decline of overall health and quality of life among patients with Parkinson's disease.</p> <p>This thesis was conducted as a descriptive literature review and 11 international articles from 2010–2018 were analysed using the inductive content analysis. The data was collected from credible databases such as CINAHL (n=8) and MEDLINE (n=3).</p> <p>The results highlighted that non-motor symptoms of Parkinson's disease had a greater effect on the health-related quality of life than motor symptoms, because of lack of awareness from both patients and healthcare professionals. As Parkinson's disease affects patients individually, a holistic patient-centred approach is needed in the care. Furthermore, there are physical, psychological, social and economic factors that help to promote the quality of life for patients with Parkinson's disease along with Deep Brain Stimulation.</p> <p>Future studies can be done on how economic factors affect the quality of life for patients with Parkinson's disease as this topic was not discussed in detail in the selected articles. Understanding healthcare professionals' attitudes and experiences of treating Parkinson's disease patients' non-motor symptoms is also a topic of interest, which might help to develop the care directed to this group.</p> |   |
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| <p>Tämän opinnäytetyön tarkoituksena oli kuvata potilaiden käsityksiä Parkinsonin taudin vaikutuksesta elämänlaatuun. Tavoitteena on tuottaa tietoa siitä, miten Parkinsonin tauti vaikuttaa elämänlaatuun, jotta voitaisiin kehittää Parkinsonia sairastavien potilaiden hoitoa. Parkinsonin vaikutukset elämänlaatuun voidaan luokitella fyysisiin, psykologisiin ja sosiaalisiin vaikutuksiin. Nämä vaikutukset ovat usein yhteyksissä toisiinsa ja aiheuttavat kokonaisvoiminnan ja elämänlaadun heikkenemistä Parkinsonia sairastavilla potilailla.</p> <p>Opinnäytetyö toteutettiin kuvailevana kirjallisuuskatsauksena, jossa analysoitiin 11 kansainvälistä artikkelia vuodesta 2010–2018 käyttäen induktiivista sisällönanalyysiä. Artikkelit löydettiin luotettavista tietokannoista kuten CINAHL (n=8) ja MEDLINE (n=3).</p> <p>Tulokset viittasivat siihen, että Parkinsonin taudin ei-motorisilla oireilla oli suurempi vaikutus potilaiden elämänlaatuun kuin motorisilla oireilla. Tämä johtui sekä potilaiden että terveysammattilaisten tiedon puutteesta. Kokonaisvaltainen potilaskeskeinen lähestymistapa on keskeistä hoidossa, sillä Parkinsonin tauti vaikuttaa potilaisiin yksilöllisesti. Tämän lisäksi on olemassa fyysisiä, psykologisia, sosiaalisia ja taloudellisia tekijöitä, jotka helpottavat edistämään potilaiden elämänlaatua mukaan lukien syväaivostimulaatio.</p> <p>Tulevaisuudessa voitaisiin tehdä tutkimuksia, jotka keskittyisivät taloudellisiin tekijöihin, jotka vaikuttavat Parkinsonin tautia sairastavien potilaiden elämänlaatuun. Lisäksi terveysammattilaisten kokemukset ja asenteet koskien Parkinsonin taudin ei-motoristen oireiden hoitoa olisi mielenkiintoinen tutkimusaihe, mikä voisi edistää Parkinsonia sairastavien potilaiden hoidon laatua.</p> |   |
| Avainsanat   | Parkinsonin tauti, elämänlaatu, potilaiden käsitykset   |

## Contents

|       |  |    |
|-------|--|----|
| 1     | Introduction   | 1  |
| 2     | Background   | 2  |
| 2.1   | Parkinson's disease  | 2  |
| 2.2   | Quality of life  | 3  |
| 3     | Purpose, aim and study questions   | 5  |
| 4     | Method, data collection and data analysis  | 5  |
| 4.1   | Method   | 5  |
| 4.2   | Data collection and study selection  | 6  |
| 4.3   | Quality assessment   | 9  |
| 4.4   | Data analysis  | 10 |
| 5     | Results  | 11 |
| 5.1   | Effects of Parkinson's disease on patients' quality of life.                             | 12 |
| 5.1.1 | Physical effects   | 13 |
| 5.1.2 | Psychological effects  | 15 |
| 5.1.3 | Social effects   | 18 |
| 5.2   | Promoting factors of quality of life from the Parkinson's disease patients' perspectives | 18 |
| 5.2.1 | Physical factors   | 19 |
| 5.2.2 | Psychological factors  | 20 |
| 5.2.3 | Social factors   | 21 |
| 5.2.4 | Deep Brain Stimulation   | 22 |
| 5.2.5 | Support from healthcare professionals  | 23 |
| 5.2.6 | Economic factors   | 24 |
| 6     | Discussion   | 24 |
| 6.1   | Discussion of the results  | 24 |
| 6.2   | Validity   | 27 |
| 6.3   | Ethical considerations   | 28 |
| 6.4   | Conclusion and suggestions for future studies  | 28 |
|       | References   | 30 |

## Appendices

Appendix 1. Framework for analysing the research articles.

## 1 Introduction

Parkinson's disease (PD) is a progressive neurodegenerative disease characterised by the loss of dopamine-producing neurons in the brain as well as numerous motor and non-motor symptoms. Consequently, patients' quality of life can be affected by various factors that can differ depending on social support, activity and environment. (Hand & Martin 2015:166.) According to the Finnish Parkinson Association (2014), there were about 16 000 people diagnosed with Parkinson's disease in Finland and the typical age of onset for PD is around 60. In 2018, the age-adjusted death rate of people with PD in Finland was the fifth highest in the world, that is 4.65 per 100 000 people or 745 total deaths per year (WHO 2018). As the average age of the population is increasing, the incidence of PD and other neurological diseases are also growing significantly (GBD 2015 Neurological Disorders Collaborator Group 2017:877). Therefore, raising awareness of the effects of PD on patients' quality of life is an important topic in the nursing field.

Parkinson's disease has a significant effect on patients' quality of life, predominantly physically and socially. Most of PD patients are at a higher chance of being unemployed because of their communication problems. This is because they often try to avoid social contacts as they are self-conscious of their symptoms. In addition, during the late stages of PD, patients often have motor function impairment, which has serious effects on their quality of life. (Dubayova et al. 2009:905.)

The etiology of PD is yet unknown, and there is no cure for this neurological disease. Nonetheless, there are pharmacological, non-pharmacological and surgical treatments that help to alleviate the symptoms and improve the quality of life for people living with Parkinson's disease. (Finnish Parkinson's Association 2015.) While Parkinson's disease symptoms and the course of the disease varies in different people, it is essential that the care directed for them are up-to-date and individually tailored. As Parkinson's disease affects the activities of daily living (ADL), one of the essential goals for the treatment is to support independent living for as long as possible. (Jackson 2019:229.)

Few studies have been done over the past 10 years to provide a comprehensive and holistic view of the experiences of people living with Parkinson's disease. Most of these previous studies tend to focus more on the clinical diagnosis and the treatment of PD.

(Maffoni, Pierobon, Frazzitta, Callegari & Giardini 2019:764; Tomagová et al. 2019:1.) Thus, the purpose of this thesis was to describe the patients' perceptions regarding how Parkinson's disease affects their quality of life and what factors promote it.

## 2 Background

### 2.1 Parkinson's disease

Parkinson's disease (PD) is the second most common neurological disease after Alzheimer's disease and is depicted by the premature death of dopamine-producing cells in the substantia nigra, a part of the midbrain, and accumulation of Lewy bodies in the neurons (Cacabelos 2017:9). Men have slightly higher PD morbidity than women and the typical age of onset for PD is 50-70 (Atula 2018). Dopamine is a neurotransmitter responsible for the control of movement and balance, thus the deficiency of it in the body is displayed as motor symptoms. The three main motor symptoms of PD are rigidity, bradykinesia (slowness of movements) and resting tremor. The motor symptoms of PD usually begin on one side of the body first and gradually increase on the other side as well. Other motoric symptoms include gait disturbances, dystonia and instability of posture. (The European Parkinson's Disease Association 2018.)

The typical motor symptoms of PD such as rigidity, bradykinesia and resting tremor, which are collectively known as Parkinsonism, can also occur in various other diseases or with the use of drugs that block the dopamine receptors. Some of these include progressive supranuclear palsy, corticobasal degeneration, multiple system atrophy and drug-induced Parkinsonism. (Käypähoito 2019.) The focus of this thesis is therefore on the Parkinson's disease itself and not on the other conditions that can cause Parkinsonism.

Although PD is often associated with its motor symptoms, it can cause numerous non-motor symptoms as well, which are believed to have a greater impact on quality of life than motor symptoms. (Lee, Woo, Lee, Cheon & Kim, 2019:2; Martinez-Martin, Rodriguez-Blasquez, Kurtis & Chaudhuri 2011:399.) These can be divided into mood disorders, such as apathy, anxiety and depression, cognitive disturbances and hallucinations

as well as autonomic disturbances such as constipation, excessive sweating, hypotension, bladder problems and sexual dysfunctions. Sleeping problems and sensory disturbances are also common such as pain and the loss of sense of taste and smell. One of the reasons behind this wide range of non-motor symptoms is believed to be caused by the fact that PD induces the degeneration of other neurotransmitters of the brain as well. (The European Parkinson's Disease Association 2018.)

Although the exact cause of neurodegeneration in Parkinson's disease is unknown, several theories point out that both environmental and genetic factors are contributory causes with the single biggest risk being the increased age. Interestingly, smoking and caffeine consumption are correlated with a lower risk of developing PD. Environmental factors include exposure to certain viruses, bacteria, toxic chemicals, pesticides, heavy metals and prior brain injuries that may alter the dopamine production in the midbrain. (The European Parkinson's Disease Association 2018.) In recent years, Parkinson's disease is witnessed to be at least partially hereditary with mutations in the primary genes causing autosomal dominant or recessive forms of PD (Cacabelos 2017:9). The hereditary cause of PD should be suspected in cases where the onset of the disease is between the ages of 30-40 (Atula 2018). However, the exact scale of how much environmental and genetic factors affect each other, and the onset of Parkinson's disease remains yet unknown (The European Parkinson's Disease Association 2018).

## 2.2 Quality of life

"Quality of life is defined as an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" (WHO 2020).

Quality of life (QoL) is a complex concept that is related to a person's overall wellbeing and contentment with life. Quality of life takes a more holistic approach in care and tends to encompass various aspects of a patient's condition and is gaining popularity in the assessment of disease impact and state. Health-related quality of life is a component of quality of life that covers physical, social and mental domains of health and is measurable at a single time or in longer intervals by the self-report of patients themselves. (Stocchi, Martinez-Martin & Reichmann 2014:13.) According to a study conducted by Forbes



(2017:28), health-related quality of life includes general health perceptions, pain, physical functioning, physical role, vitality, social functioning, emotional functioning and mental health.

There are numerous assessment tools for quality of life and some are specially designed for a particular disease. With regards to Parkinson's disease, some of these questionnaires are the Parkinson's Disease Questionnaire (PDQ-39) and the Parkinson's Disease Quality of Life Questionnaire (PDQL). (Opara, Broła, Leonardi & Błaszczuk 2012:376.) There is also the Non-Motor Symptoms Scale (NMSS), which is used to evaluate the effects of non-motor symptoms on health-related quality of life of people with Parkinson's (Martinez-Martin et al. 2011:400).

Several studies have been conducted previously on how Parkinson's disease has affected the patients' quality of life and their coping strategies. Some of these include a study conducted in Japan, which investigated the quality of life amongst people with Parkinson's disease. The study revealed that building a social network or support system as well as having good communication could play a big role in improving patients' quality of life. (Takahashi, Kamide, Suzuki & Fukuda 2016:545.) Another study written by Pappa, Doty, Taff, Kniepmann and Foster (2017:82), showed that motor and non-motor symptoms of PD have a negative effect on patients' quality of life as well as increasing distress among the caregivers. The care partners of Parkinson's patients are at a high risk of caregiver burden hence deteriorating personal health, weakened social engagement and more depressive symptoms, which in turn negatively affect the person with Parkinson's disease. Similar results were mentioned in another study, which investigated factors that affects health-related quality of life amongst Estonian people with Parkinson's disease. Motor and non-motor aspects were found to be the main factors contributing to low health-related quality of life. (Kadastik-Eerme, Muldmaa, Paju, Rosenthal & Taba 2015: 5-6.)

Overall, Parkinson's disease has a direct impact on the movement of the body parts. However, it is imperative to note that the symptoms and the progression of the disease are different amongst the individuals, in terms of the impact it has on the functional capabilities, quality of life, activities of daily living (ADL) and social life. Nonetheless, the progressive nature of Parkinson's will inevitably deteriorate the patient's quality of life (Martine, Jean -Francois & Christian 2016:685-686.) However, there are several ways of

coping with the illness that can optimise the quality of life for people living with the disease as well as their loved ones. Being diagnosed with Parkinson's can lead to several different unusual reactions and emotions, which eventually affect one's normal routine. (Moawad 2020.) Having a positive attitude and taking part in different kinds of activities are some of the coping strategies that PD patients and their caregivers used to adapt to their difficulties in their daily routines. (Navarta-Sanchez et al. 2016:1960.)

### **3 Purpose, aim and study questions**

The purpose of this thesis was to describe how Parkinson's disease affects patients' quality of life. The aim of this thesis is to produce knowledge on how Parkinson's disease affects the patients' quality of life in order to develop the care directed to people with Parkinson's disease.

The study questions are as follows:

1. How does Parkinson's disease affect the quality of life from the patients' perspective?
2. What factors promote the quality of life for people with Parkinson's disease from the patients' perspective?

### **4 Method, data collection and data analysis**

#### **4.1 Method**

This thesis is using a qualitative approach in the shape of a narrative or descriptive literature review. There are many variations among literature reviews as they are conducted for different purposes. They can be divided into three categories, which are narrative or descriptive literature reviews, systematic literature reviews, and meta-analysis (quantitative meta-analysis and qualitative meta-synthesis). (Stolt, Axelin & Suhonen 2015:8.) Descriptive literature reviews can be defined as an objective, in-depth summary and critical analysis of a certain amount of relevant literature about a specific topic (Cronin, Ryan & Coughlan 2007:38).

The purpose of the descriptive literature review is to deliver a contemporary and comprehensive basis for readers about the research topic and underline the importance of novel research. One of the major strengths of the descriptive literature review lies in its capability to identify and acknowledge gaps or inconsistencies in the existing knowledge and evoke new research questions or hypotheses. (Cronin et al. 2007:38.) Additionally, it also tends to explain what is already known about the topic, the key concepts and their interrelated connections (Kangasniemi et al. 2013:294).

According to Cronin et al. (2007:38), a high-quality literature review uses various sources to find the relevant data, it is well written and contains little if any personal biases. Consequently, a high-quality literature review requires up-to-date, relevant and reliable sources. Therefore, academic journals, books and doctoral theses should be preferred over professional journals, newsletters, pamphlets, social media or anecdotes. (Parahoo 2014:114.)

In order to get reliable results, first one must have a comprehensive understanding of the methods of descriptive literature reviews. Understanding the process of conducting a literature review facilitates the comprehension and critical analysis of selected research articles and is also a prerequisite for its successful conduction. (Kangasniemi et al. 2013:298.) During the conduction of a literature review, a systematic approach is necessary. Furthermore, the process must be described as simple as possible, in order for readers to be able to evaluate its reliability and implementation during each stage. (Stolt et al. 2015:23.)

#### 4.2 Data collection and study selection

The data was collected from credible electronic databases such as CINAHL and MEDLINE. MeSH subject headings were used to find different variations of the search terms. In addition, the accuracy of the search terms was assessed by the informatician of Metropolia UAS. The Boolean connectors “AND” and “OR” were applied when searching for the articles in the databases. The search terms and the whole search process is shown in figure 1. The language of the research articles was limited to English. Further limitations can be seen below in table 1.

Table 1. Selection criteria for the articles

| Inclusion criteria                    | Exclusion criteria                     |
|---------------------------------------|--|
| -English language                     | -Other languages than English          |
| -Research articles                    | -Non-research articles                 |
| -Peer-reviewed                        | -Not peer-reviewed                     |
| -Articles published between 2010-2020 | -Articles published before 2010        |
| -Answered the research question/s     | -Research question/s were not answered |

The data were selected based on the previously mentioned inclusion and exclusion criteria (table 1). By using the search terms, as shown in figure 1, a total of 629 hits were found from CINAHL and 384 from MEDLINE. After this, the inclusion and exclusion criteria were used to narrow down the articles: first based on their topic, next based on their abstract and finally based on their full text.

As a result of the database search, a total of 17 articles were chosen based on full text, which had been published between 2004-2019. Since most of these articles were published after 2010, the articles that were published before this year were excluded in order to get the most up-to-date research articles. After including the timeframe as a limiting factor, three articles that were published before 2010 were excluded. Following this, the quality of the remaining 14 articles and their journals were checked by using appropriate evaluation tools and three additional articles were excluded. In the end, 11 articles were selected to be analysed using the inductive content analysis.

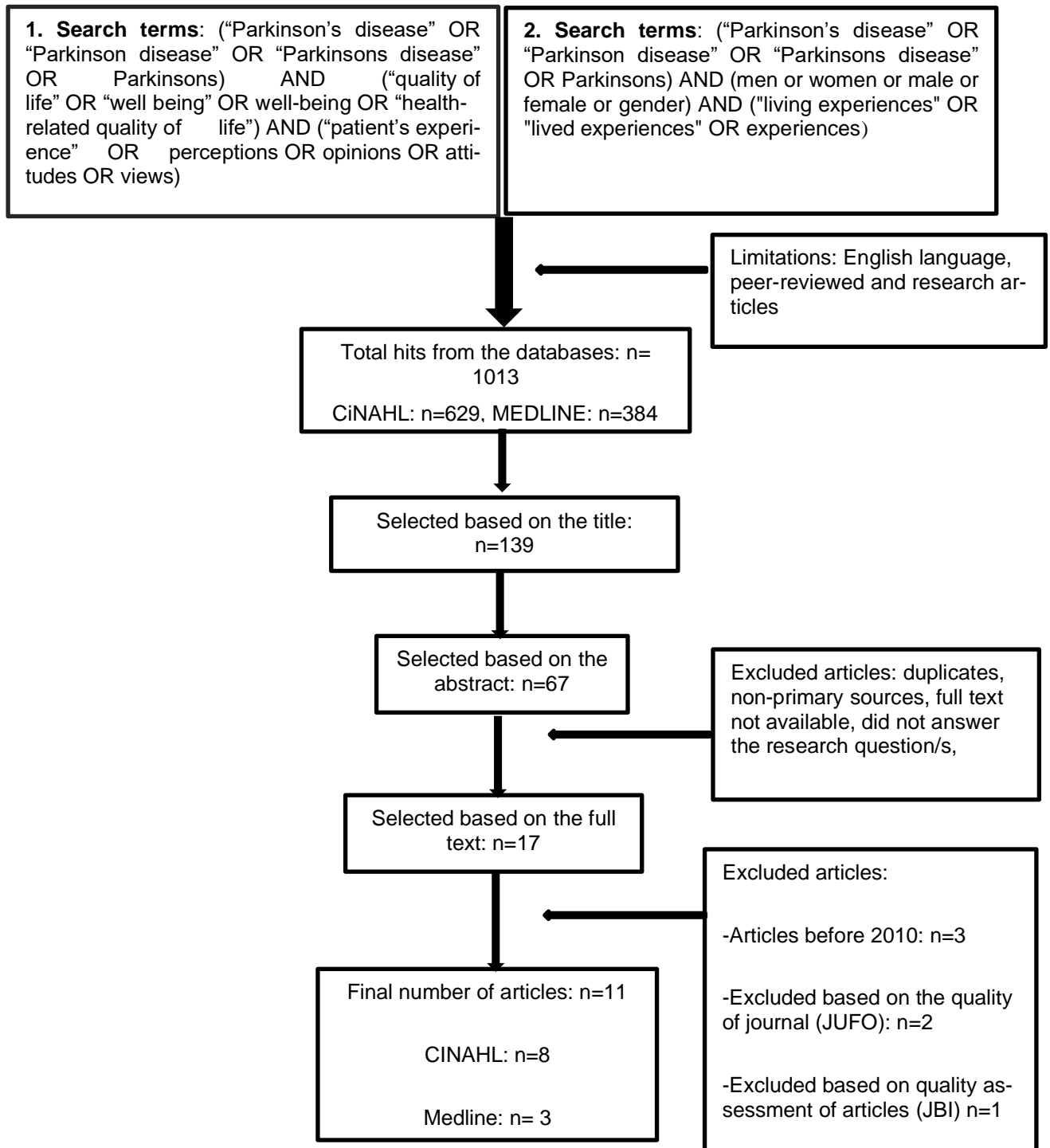


Figure 1. Literature search from different databases

### 4.3 Quality assessment

After the studies are selected through a database search, the next phase is to assess their quality. The purpose of the quality assessment is to evaluate the coverage of information and the representativity of the results. In addition, it helps to facilitate how the information of primary sources are aligned with one's own research questions and problems. (Stolt et al. 2015: 28.)

In this thesis, Julkaisufoorumi (JUFO) was used to check the quality of journals that had published the selected research articles. JUFO is a classification publication forum system that is used to evaluate the scientific research output. This system can be used as a quality indicator of journals, which publishes research articles. Evaluation is done using the four-level classification rating system to rate major foreign and domestic publication channels of all disciplines. These levels include 1= basic level, 2= leading level, 3= highest level and 0= publication channels that do not meet the criteria for level 1. (Julkaisufoorumi.)

After assessing the journals of the selected articles, we applied Joanna Briggs Institute's (JBI) checklists to evaluate the quality of the articles themselves. JBI is a non-profit organization that specializes in producing literature for evidence-based healthcare and creating methods to assess and summarise diverse forms of evidence (Stolt et. al 2015:120). Since all but one of the 14 studies were qualitative, we used JBI's critical appraisal checklist for qualitative research in order to assess their quality. For the remaining one quantitative study, we used the JBI's checklist for studies reporting prevalence data. We then gave a numerical ranking (as seen in appendix 1) to the articles based on the questions of the checklists. (Joanna Briggs Institute 2020.)

Two of the selected articles were excluded based on their quality of journal, which were rated 0 by JUFO's four-level rating system. Additionally, the one quantitative study was excluded based on JBI-criteria using the checklist for studies reporting prevalence data. This was because the methodology and the data collection process of this particular study was not discussed in detail. Altogether three articles were excluded based on quality assessment, which meant 11 articles were finally selected for the inductive content analysis.

#### 4.4 Data analysis

In order to answer our study questions, we used inductive content analysis to analyse the selected articles. Content analysis is a research method that is used for identifying the patterns of communication within some given data. Researchers use content analysis to systematically collect data and analyse the meanings and relationships of certain texts, themes or concepts. (Columbia Public Health 2019.) Content analysis can be used in either an inductive or deductive way. Both ways involve preparing, organizing and reporting the outcomes. Deductive content analysis is used for testing categories in different time periods or previous theories in different circumstances, while inductive content analysis involves identifying the categories, themes and concepts to report the results. (Elo and Kyngäs 2008:107.)

According to Elo and Kyngäs (2008:107), the inductive content analysis is used when there is a gap in the previous knowledge or when the body of knowledge is fragmented. The inductive approach moves from the specific to the general so that every case is first observed and then merged into general statements. In order to organise and find patterns in the qualitative data, one must use open coding, create categories and abstractions.

In the first part of the analysis, we created a table for the summary of research articles selected based on the full text that we intended to analyse (appendix 1.). Here we have listed the name of the authors, publishing year, country, data collection and analysis methods and the main outcomes of the articles. Following this, we created a content analysis table to analyse and synthesise our findings. Meaning units - sentences or themes that are written in the abstract, result or discussion part - were searched in the selected articles to find answers to our research questions (Stolt et al. 2015:89). These were then summarised and rephrased into condensed meaning units as well as subcategorised based on similarity. In the final stage, the similar sub-categories were grouped together into larger themes, which were named as main categories. Below is an example of the content analysis table.

Table 2. An example of inductive content analysis

| Meaning unit  | Condensed meaning unit   | Sub-category          | Main category    |
|---|--|-----------------------|------------------|
| "I feel as if you know something's going to snap or burst and it just sort of finishes you really, it's so severe...Like yesterday was dreadful. I felt like shooting myself." (11) | The pain reached unbearable levels, which made me to develop suicidal thoughts.  | Pain and discomfort   | Physical effects |
| "I feel that I am not the authority figure in the house that I used to be. I feel my power is fading slowly. My children and grandchildren wont listen to me any more." (5)         | I am not the same authority figure as I used to be. My power over my family is fading, my children and grandchildren won't listen to me anymore. | Altered relationships | Social effects   |

## 5 Results

The selected articles that were analysed using the inductive content analysis (n=11) were all qualitative studies from diverse countries around the world. However, most of them were conducted in Europe, especially in the UK (n=4) and Scandinavian countries such as Sweden (n=3) and Denmark (n=1). The remaining studies were conducted in USA (n=1), Iran (n=1) and Jordan (n=1). The table for selected articles for analysis can be seen in appendix 1.

The method in the selected articles were all interviews and most of the participants had mild to moderate stages of Parkinson's disease. The total amount of the participants were n=176 and both genders were almost equally represented, except in the study conducted by Gibson & Kierans (2016) where all participants were men. The age of participants varied from the early thirties to nineties while most mean ages were between 60-70.

In this chapter, the results are divided into two sections based on our research questions, which are 1) How does Parkinson's disease affect the quality of life from the patients'



perspective? and 2) What factors promote the quality of life for people with Parkinson's disease from the patients' perspective? The main categories and sub-categories that were derived from the content analysis table are used in this part to answer our research questions.

### 5.1 Effects of Parkinson's disease on patients' quality of life from patients' perspective

By using the inductive content analysis, similar sub-categories were grouped to form three main categories that illustrated how Parkinson's disease affects the quality of life from patients' perspectives. These main categories included physical effects, psychological effects and social effects. The sub-categories under these main categories can be seen below in table 3.

Table 3. Main categories and subcategories of effects of Parkinson's disease on patients' quality of life.

| <b>Main categories</b> | <b>Sub-categories</b>  |
|------------------------|--|
| Physical effects       | <ul style="list-style-type: none"> <li>-Loss of autonomy</li> <li>-Motor symptoms</li> <li>-Non-motor symptoms</li> <li>-Progressive decline of physical health</li> <li>-Transportation issues</li> <li>-Falls and related injuries</li> <li>-Reduced work capacity</li> <li>-Communication problems</li> </ul> |
| Psychological effects  | <ul style="list-style-type: none"> <li>-Changes in one's self-image</li> <li>-Mixed emotions</li> <li>-Sleeping problems</li> <li>-Apathy</li> <li>-Cognitive impairments</li> <li>-Loss of motivation and hope</li> </ul>   |
| Social effects         | <ul style="list-style-type: none"> <li>-Altered relationships</li> <li>-Social stigma</li> <li>-Social isolation</li> </ul>  |

### 5.1.1 Physical effects

Studies revealed that motor symptoms of Parkinson's disease (PD) such as bradykinesia, tremor, gait disturbances and balance impairments had a negative impact on participants' mobility and restricted their physical activities both inside and outside their homes (Gibson & Kierans 2016:535; Nazzal & Khalil 2017:78; Sjö Dahl, Westergren, Åström, Edberg & Hagell 2018:3). Particularly younger participants with Parkinson's disease reported that motor symptoms such as bradykinesia and gait disturbances made them feel older than their respective ages (Gibson & Kierans 2016:536). Motor symptoms of Parkinson's disease, such as reduced balance control, were also associated with frequent falls and injuries (Leavy, Roaldsen, Nylund, Hagströmer & Franzén 2017:82).

Experiences and fears of falling and related injuries were common among people with Parkinson's disease. This also influenced their behaviour towards physical activities as they tried to minimise the risk of falls by restricting their activity levels. This, however, caused a downward spiral as their health declined by reduced or lack of physical activities and was linked to decreased health-related quality of life. (Leavy et al. 2017:82.)

Parkinson's disease has a major impact on patients' day-to-day life and was associated with the loss of autonomy. Patients felt increasingly dependent on their families and caregivers for managing activities of daily living such as taking baths, brushing their teeth, dressing or buying their medicines. This sense of incompetency made them feel embarrassed, belittled and less confident in themselves (Nazzal & Khalil 2017:77; Sjö Dahl et al. 2018:4.) One participant also expressed fears from the loss of autonomy as she was afraid of not being able to get help in time of emergencies (Sjö Dahl et al. 2018:3), while others had a hard time adjusting to this new role as they were not used to a high level of dependency (Den Oudsten, Lucas-Carrasco, Green & Whoqol-Dis Group 2011:2496).

The progressive impact of Parkinson's disease on physical, psychological and cognitive functioning inevitably manifested itself in the lives of patients by decreasing their ability to perform physical activities (Sjö Dahl et al 2018:2). For some participants, the decline of functional capabilities was so drastic, compared to the initial phase of the disease, that they were unable to carry out ADLs without help from their families or caregivers (Soleimani, Bastani, Negarandeh & Greysen 2016:191). According to Gibson & Kierans

(2016:543) findings, the loss of physical abilities among men was sometimes so quick that they could not compensate all of them in time.

The progressive nature of PD was also the main reason behind the reduced work capacity of patients, which led to early retirement or loss of their jobs. The loss of one's job had a negative impact on patients' social wellbeing as they were not able to replace the social contacts of their workplace with new ones. (Soleimani et al. 2016:192.) Communication problems were also a factor that contributed to reduced work capacity as participants reported of challenges with everyday communication. PD had a negative effect on the tone of voice and made it harder for patients to be understood by others and perform speeches. (Soleimani et al. 2016:193; Sjö Dahl et al. 2018:4.)

Another factor that limited the patient's quality of life was transportation issues, which were also linked to loss of autonomy caused by PD symptoms (Haahr, Kirkevold, Hall & Østergaard 2010:1234). Not being able to drive a car was associated with increased social isolation as participants were not able to move around as easily anymore, which meant that the threshold for leaving their house increased significantly (Sjö Dahl et al. 2018:4; Den Oudsten et al. 2011:2495). Alternatives for driving a car such as public transport were deemed inconvenient by most of the participants since it required a great deal of planning beforehand (Sjö Dahl et al. 2018:4).

Non-motor symptoms of PD such as fatigue, pain, constipation, incontinence, loss of sense of smell and taste, sexual dysfunctions and speech problems were also reported by people with Parkinson's disease, which affected their physical functioning (Den Oudsten et al. 2011:2495; Gibson & Kierans 2016:535; McClurg et al. 2016:3; Soleimani et al. 2016:193; Twomey, Stuart & Baker 2018:304; Westergren, Hagell, Wendin & Sjö Dahl 2016:203).

Pain is a common non-motor symptom of PD and was correlated with decreased health-related quality of life among patients with Parkinson's. Pain affected all aspects of a participants' life, particularly physically and psychosocially. It was associated with the loss of hope, negative moods, sleep problems, social isolation, depression and suicidal ideation. The adaptation of a holistic and patient-centred approach was recommended in the care in order to better comprehend the pain among patients with Parkinson's disease. (Twomey et al. 2018:307.)

Severe forms of fatigue and diminished energy were reported by several patients with PD. (Gibson & Kierans 2016:539; Sjö Dahl et al. 2018:3.) Participants felt that these limited their ability to carry out even their most basic ADL's such as taking care of their personal hygiene, let alone the more demanding physical activities such as gardening and car maintenance (Gibson & Kierans 2016:539).

Loss of sense of smell and taste were described by the participants in the study conducted by Westergren et al. (2016:203) which resulted in a limited amount of foods to eat. Even spicy and salty food were perceived as bland by the participants and they were not able to enjoy their favourite dishes anymore. Participants also felt decreasing enjoyment eating together with others.

Constipation was considered as an under-reported and neglected symptom of PD, but which had a major negative impact on patients' perceived quality of life. The negative effect of constipation on patients' lives were displayed through emotional, psychological and social outlets. Constipation caused increased and longer visits to toilet without achieving the wanted results. The stool was reported to be small pellets, which resulted in straining, pain and discomfort. One participant mentioned that constipation prevented him from going out of his home since he did not have control over his bowel. (McClurg et al. 2016:3.) Similar results were reported by Gibson and Kierans (2016:536) regarding incontinence among men, where participants were watchful of the slightest signs of urination and avoided public places without access to the toilet.

Sexual dysfunctions such as loss of libido and erectile dysfunction were also reported by almost all men who had Parkinson's. However, the symptoms of sexual dysfunctions differed among participants: while one participant reported that he suffered from the loss of libido during sexual intercourse, another participant reported that libido was not affected by PD, while performance was. (Gibson & Kierans 2016:537.)

### 5.1.2 Psychological effects

Being diagnosed with Parkinson's was a major shock for the participants. There was a denial process that lasted for a time. Some of these people living with Parkinson's questioned the disease and kept asking "why me?" (Nazzal & Khalil 2017:76-77.) Diagnosis with a chronic illness can be a remarkable stressor. Often an individual's self-image is

altered and changes to adjust to living with this new illness. Psychologically, this adjustment may pose an intense challenge that can affect the management and the course of the disease. (Soleimani et al. 2016:194.)

People with Parkinson's also experienced mood problems that affected their psychological health. Some of them became too emotional and could cry without any particular reason. (Den Oudsten et al. 2011:2501.) Increased anxiety in different places, times and situations was also reported by people with Parkinson's. Anxiety disorders significantly affected the impairments in cognitive, functional, motor and social performances of the people with Parkinson's disease. This resulted in the reduction of the quality of life and increased level of care dependency amongst people with Parkinson's. Some of the persons with PD were worried about their future due to the progressivity of the disease, which brought fear and anxiety among them. (Soleimani et al. 2016:191.)

The severity of the disease increased dependency on care and this caused bitterness and shame for patients. The changes in their physical and mental health impacted their self-esteem. The feelings of humiliation, belittlement, insecurity and lack of confidence were experienced by people with Parkinson's. (Sjödahl et al. 2018:3-4.) PD affected the body's intimate functions such as drooling, incontinence and sexual dysfunction, which had a bigger impact on men's masculine self-image than the typical motor symptoms (Gibson & Kierans 2016:536). Most of the persons with PD expressed that the perceptions of their body image were altered after they were diagnosed with PD and the appearance of the signs and symptoms. Gait disturbances, imbalance and changes in facial expressions triggered many fears for people with Parkinson's disease. Patients' awareness and how they perceived themselves determined a person's social outcome and their quality of life. (Soleimani et al. 2016:192-193.)

Sleep and rest were very important for people with Parkinson's, as this influenced their quality of life. Participants reported that they did not sleep enough because they had to wake up to take their medications and then go back to sleep again. They also mentioned that sometimes the side effects of the medication affected their sleep. (Den Oudsten et al. 2011:2494-2495.)

People with Parkinson's highlighted that they felt embarrassed with some of their symptoms such as bowel dysfunctions and tremors. Some of them expressed how they felt embarrassed for having flatulence or taking laxatives regularly. Dealing with constipation

caused discomfort and lowered their daily moods. Talking about constipation was also considered “taboo” and embarrassing, which they wanted to avoid talking about it with their healthcare professionals. (McClurg et al. 2016:3-6.) The inability to control the shaking caused tension and nervousness. It was difficult for the people with Parkinson’s to eat together with others and some of them could not go to work because they would feel ashamed and embarrassed of their shortcomings and disabilities. (Soleimani et al. 2016:192; Westergren et al. 2016:203.)

Apathy is a psychological symptom experienced by people with Parkinson’s and they described it to be worsening with the severity of the disease. PD patients complained of not always having the energy and lacked the initiative to exercise or get anything started. They didn’t have the same kind of interests in the leisure activities that they used to do before the disease. (Haahr et al. 2010:1233; Leavy et al.2017:86.)

In addition, several people with Parkinson’s described experiencing cognitive impairment. They had problems with remembering, concentrating, and communicating. They would forget the names of the person/s talking to them or even finding the right words to say. Some were worried that they would lose the capacity to love their kids and grandchildren. (Den Oudsten et al. 2011:2497; Gibson & Kierans 2016:540; Sjö Dahl et al. 2018:3.) Others had memory problems when performing their daily activities like cooking and shopping. They had to write down everything and try not to forget to bring the shopping list with them. (Westergren et al. 2016:203.)

Most people with Parkinson’s, especially those at the end-stage, lost motivation and hope. Their physical active lifestyle deteriorated (Leavy et al. 2017:86) and they would spend most of their time alone at home and avoid interactions with their close ones. (Soleimani et al. 2016.) Motor symptoms such as gait disturbances and tremors and non-motor symptoms like pain and constipation brought the feeling of helplessness and hopelessness. They felt depressed and sad for not being able to do what they wanted. Some of them admitted having suicidal thoughts, they saw no point in living. Others admitted taking anti-depressants for their depression. (McClurg et al. 2016:4; Nazzal & Khalil 2017:77; Sjö Dahl et al. 2018:3; Twomey et al. 2018:303).

### 5.1.3 Social effects

Parkinson's disease altered family relationships; some people with Parkinson's described their partners being away most of the time to avoid responsibilities. Some of the families had to redistribute their household and family responsibilities. They did this because they wanted their families to treat them just as they used to and not to give them special attention. (Sjödahl et al. 2018:3.) As the disease progressed, people with Parkinson's described the feeling of loss of control over their families (Nazza & Khalil 2017:77).

Participants also expressed that people would sometimes mistake them for alcoholics, stare at them in peculiar ways and sometimes laugh or even make hurtful comments because of their involuntary movements. The feeling of not having control over the motor symptoms like gait and tremors resulted in the social stigma. Participants would attempt to hide their shortcomings and disabilities by isolating themselves. (Leavy et al. 2017:85; Nazza & Khalil 2017:76; Sjödahl et al. 2018:4.)

People with Parkinson's described how their physical capacity and balance performance had declined due to the severity of the disease. They lost motivation of doing or attending any group interactions that they used to go to. (Leavy et al. 2017:86.) Others could not participate in any social events because of the pain they were experiencing (Twomey et al. 2018:304). People with Parkinson's socially isolated themselves because they felt embarrassed of their uncontrollable symptoms such as speech problems and facial expressions. (Sjödahl et al. 2018:4).

## 5.2 Promoting factors of quality of life from the Parkinson's disease patients' perspectives

Six main categories emerged from the content analysis, which promoted the quality of life from the PD patients' perspective: physical factors, psychological factors, social factors, economic factors, Deep Brain Stimulation (DBS) and support from healthcare professionals. The main categories and sub-categories of the content analysis for promoting factors can be seen below (table 4).

Table 4. Main categories and subcategories of promoting factors of quality of life from the patients' perspective.

| <b>Main categories</b>                | <b>Sub-categories</b>   |
|---------------------------------------|---|
| Physical factors                      | -Physical exercises<br>-Physical coping strategies<br>-Management of constipation   |
| Psychological factors                 | -Optimism and accepting the disease<br>-Psychological coping methods<br>-Self-efficacy and maintaining autonomy<br>-Spiritualism/religion |
| Social factors                        | -Music therapy<br>-Family support<br>-Communication support<br>-Group activities  |
| Economic factors                      | -Financial resources  |
| DBS                                   | -Positive effects of DBS  |
| Support from healthcare professionals | -Appropriate care<br>-Positive attitude of healthcare professionals<br>-Early diagnosis and interventions                                 |

### 5.2.1 Physical factors

Physical exercising was regarded by patients as one of the key methods that helped them to maintain their health-related quality of life and adapt to the symptoms of Parkinson's disease. Patients used physical activities both as a short and long-term strategy to combat PD symptoms and their progression. Furthermore, physical exercise programs helped the participants to improve their self-confidence and made them rethink their physical capabilities and limitations. (Leavy et al. 2017:81.) In the study conducted by Twomey et al. (2018:306), patients reported doing physical exercises despite the initial pain associated with it, because they believed that the benefits of physical exercises outweighed the pain and helped them to improve their mobility and fitness. In the long term, physical exercises were believed to be source of a pain relief, because the alternative of staying home and doing nothing was associated with exacerbation of PD symptoms.



Participants in the study conducted by Sjö Dahl et al. (2018:5) compensated for their lost physical functioning by doing chores sitting down and avoiding reaching for things or other specific situations altogether, in order to minimise the risk of falls and related injuries. They also took showers instead of baths and bought cooking and cleaning services when they were unable to do it themselves. In addition to these, participants in the aforementioned study used different kinds of assistive devices in their daily lives, which helped them maintain their independence. These included alarms to remind them when they had to take their medicines, special chairs for showers, canes for walking and maneuvering wheelchairs with remote controls for moving around. Other physical coping strategies that PD patients viewed as beneficial were using heat for muscle relaxation (Twomey et al. 2018:306), avoiding sitting for too long (Leavy et al. 2017:85) and taking a nap during the day (Den Oudsten et al. 2011:2494).

With regards to constipation, dietary changes were used by participants to treat constipation. Some of the dietary changes used included the use of prune juice and eating more fruits, vegetables, roughages, brown bread and Weetabix. Another constipation management method was having a higher fluid intake during the day. This was supported by filling bottles with water or juice and using them throughout the day, taking water with their medicines and drinking alternatives to water (soda water, juices or tea). Most of the participants reported that this helped them to ease out their constipation. Furthermore, abdominal massage was considered an effective treatment for the constipation, particularly when patients were not fond of using medications such as laxatives. (McClurg et al. 2016:4-5.)

### 5.2.2 Psychological factors

Patients with PD described promoting their psychological well-being by having a positive attitude. They tried being optimistic, enjoying the present and tried not to think about the future by focusing more on the things that they were still able to do. They lived in the present and stopped having high hopes and expectations for their future. (Den Oudsten et al. 2011:2498; Haahr et al. 2010:1233; Sjö Dahl et al. 2018:4.) Some of them remained in control of their life by overcoming their pain and accepting living with it (Twomey et al. 2018:303). People with Parkinson's stated that accepting the diagnosis and starting the medications as early as possible helped a lot in coping with the disease (Nazzal & Khalil 2017:78).

Participants who had joined a physical training program stated having more confidence in self-efficacy. They would do things on their own and not ask anyone for help. (Leavy et al. 2017:86.) Persons with PD reported to have been active in society and doing things that they were still able to do. This made them feel useful to society and helped maintain their self-esteem. (Den Oudsten et al. 2011:2503.) Self-efficacy was also seen in participants who were able to cook and eat independently (Westergren et al. 2016:204).

People with Parkinson's mentioned spiritualism to be a contributor to quality of life. Some of them reported that they believed in the higher power to provide some guidance to them as this helped in forgetting the disease. (Den Oudsten et al. 2011:2503.) They saw the illness as something that drew them closer to God. They viewed it as a test from God and so they had no choice but to abide by God's will. The participants described these feelings to have brought them comfort and helped them overcome the challenges. (Nazzal & Khalil 2017:78).

According to a study done by Sjö Dahl et al. (2018:4), people with Parkinson's used different psychological strategies to cope with various situations. These included the ability to foresee and plan, compensating for lost functioning, maintaining positive attitudes, using downward comparisons and accepting support from the healthcare professionals. They also used self-deception: they would convince themselves that the situation was not as bad as it was. Doing one thing at a time was a strategy adopted by people with Parkinson's in their everyday lives. They tried to avoid situations that involved the complex combination of motor and cognitive functioning. (Leavy et al. 2017:85.) Participants reported that they felt relieved after they talked about their struggles with constipation to someone. This helped in reducing stress and anxiety hence enabling the digestive system to work more efficiently. (McClurg et al. 2016:6.) By talking more about their incontinence problems, it helped them see it as a part of the disease process and not a personal failing (Gibson & Kierans 2016:537).

### 5.2.3 Social factors

A study done by Stegmöller et al. (2017) on a group of participants who attended a music therapy, reported that the participants viewed the gatherings as fun and engaging. They saw it as a support group through which they could build new friendships. The participants mentioned learning the importance of exercise in promoting their quality of life.

They learned how to use their voices and breath correctly, which strengthened their muscles and coordination. This helped them lessen any bad effects of poor swallowing or choking in the future when the disease progressed. The participants acknowledged that the program helped them improve their physical health in terms of talking better and louder, good posture and having more stamina when standing or walking. Other participants described how deep breathing exercises had helped them in relaxing, reducing back pain and minimising stress. Additionally, having communication support was also important to the well-being of people with Parkinson's disease. For those who were unable to leave their home due to mobility problems or non-motor symptom, they would use the internet to feel connected to the world. (Den Oudsten et al. 2011:2502.)

Persons with PD reported that getting support from their families was extremely important to them. This helped them in adapting and overcoming the challenges of the illness. They reported getting help from their family members, close friends and neighbours. (Nazzal & Khalil 2017:79).

According to a study done by Leavy et al. (2017:87), group training was perceived to play an important role (Den Oudsten et al. 2011:2504) in adhering to training programmes among persons with PD. It also helped in developing a sense of belonging among the people sharing a PD diagnosis. Training with others who shared similar challenges was identified as reassuring and inspiring. They all understood the limitations associated with Parkinson disease and so they were able to support one another (Stegmüller et al. (2017). Participants who attended different support meetings admitted using downward comparisons to compare themselves with those who were worse off. This method helped them realise how their situation was not as bad as it seemed. (Sjödahl et al. (2018:5.)

#### 5.2.4 Deep Brain Stimulation

In the study conducted by Haahr et al. (2010:1231) participants described a major positive effect on their quality of life after undergoing Deep Brain Stimulation (DBS). One participant who underwent DBS surgery, described her initial feelings postoperatively "as if I had never had anything wrong with me". After undergoing DBS participants noticed significant positive changes in their symptoms: some were able to walk again without

using wheelchairs, and basic ADLs were possible again such as dressing, undressing and turning in bed.

Moreover, DBS helped the participants to be more spontaneous, which promoted the participants' social lives. As a result, they were able to stay up for longer periods and were not as dependent on medications anymore. Participants also noted improvements in the symptoms of "off" periods when the PD medications stopped working. Although there was some variation among participants regarding the positive effects of DBS, an overall improvement in physical functioning was noted by all participants after the treatment. (Haahr et al. 2010:1231-1232.)

However, undergoing the DBS procedure was associated with dramatic changes in patients' lives and their bodies within the first year of the treatment. While some participants adapted to these changes remarkably well, others were less fortunate. Some of the participants reported developing new symptoms and a decline in mental and physical health after the treatment. Living in the present, challenging one's own abilities and support from family and healthcare professionals were factors that helped the patients to adjust to the changes. On the other hand, focusing too much on the disease, lack of initiative and self-confidence hindered the participants' adaption process after the treatment. (Haahr et al. 2010:1235.)

#### 5.2.5 Support from healthcare professionals

Wishing to have at least one healthcare professional to turn to for support was stressed by participants in the study carried out by Sjö Dahl et al. (2018:5) as they thought that the time between clinic visits was too long. One participant noted the importance of the support she got from her physician and her positive attitude towards her, which she thought was extremely helpful. Studies also noted the importance of early diagnosis and interventions as this helped participants to finally realise what was wrong with them and what kind of management they needed for their symptoms. (Nazzal & Khalil 2017:78; So-leimani et al. 2016:193.)

Additionally, studies revealed that a more holistic and patient-centred approach in the care was needed for PD patients (Den Oudsten et al. 2011:2501; Twomey et al. 2018:305). Medical assessments and appointments should look at the person as a whole

and take their home environments into consideration to get an idea of what kind of care needs are required (Den Oudsten et al. 2011:2501). Similar results were reported by Sjö Dahl et al. (2018:6), which stressed the importance of a shift from biomedical to a more needs-based approach in care. This helped to better comprehend the impacts of living with PD, the interventional outcomes from patients' perspective and facilitated a more patient-centred care.

In the study conducted by McClurg et al. (2016:6) the importance of open communication was stressed. By helping patients to realise the possibility of developing PD symptoms such as constipation, which is considered a "taboo" by some, helped the patients to discuss their other non-motor symptoms as well. This also provided an opportunity for healthcare professionals to guide patients about coping strategies such as abdominal massage for constipation, which had a positive impact on their quality of life.

#### 5.2.6 Economic factors

Economic factors such as having enough financial resources were described to contribute to promoting quality of life. Having sufficient financial resources helped persons with PD adapt their surroundings to their disabilities. Participants also mentioned how not having enough financial resources limited them in participating in their hobbies. Persons with PD also stated how the assistive equipment contributed to the quality of life. (Den Oudsten et al. 2011:2504.)

## 6 Discussion

### 6.1 Discussion of the results

According to the results of our thesis, Parkinson's disease (PD) has a wide range of effects on patients' lives, both physically and psychosocially. This inevitably leads to decreased quality of life due to the progressive nature of the disease. Concurrently, the overall decline of health due to PD triggers a series of reactions and coping strategies among patients that compels them to adapt to the disease. (Sjö Dahl et al. 2018:4; Twomey et al. 2018:303)

The coping methods adapted by patients depended on their previous life experiences and attitudes. For instance, participants who had fewer positive experiences of physical activities did not use it as a coping method, while those who had more positive experiences used it regularly as a counteract against their motor symptoms. However, not all coping methods adopted by the patients were beneficial for them, as some patients tried to accept pain as part of their life rather than seeking help from the healthcare professionals. (Twomey et al. 2018;303-304.)

Other coping methods involved having a positive attitude, accepting the diagnosis, starting the medications early, joining different types of group activities and resorting to religion and spiritualism. (Den Oudsten et al. 2011:2498–2503; Haahr et al. 2010:1233; Nazzal & Khalil 2017:78; Sjö Dahl et al. 2018:5.) Group activities such as music therapy (Stegmüller et al. 2017:423–424) and balance training programs (Leavy et al. 2017:85-86) helped the participants in establishing a social community and a sense of belonging. Participating in these events helped patients to socialize and talk about their problems without feeling ashamed of their symptoms. However, some participants were not fond of group activities as they felt scared and anxious about seeing people who had more severe cases of PD (Sjö Dahl et al. 2018:5).

The physical and psychosocial effects of PD symptoms on patients were often interlinked with each other: while the physical decline in Parkinson's caused negative emotions among patients, such as embarrassment, the negative emotions exacerbated the decline of physical activities. This was due to the fact that negative emotions were associated with social disconnectedness (Soleimani et al. 2016:193). This is a clear example of the vicious circle that symptoms of PD created for patients and highlights the importance of taking into consideration the overall impact of Parkinson's disease and the interconnectedness of its symptoms on the decline of health.

Changes in one's self-image were common among people with PD. Gibson and Kierans (2016:536) reported that Parkinson's disease eroded the masculine self-image of men and made them feel embarrassed about their symptoms. Similar results were reported in a previous study conducted by Fleming, Tolson and Schartau (2004:517-518) about the effects of Parkinson's disease among women, who mentioned that they had issues with their body-images, which threatened their sense of womanhood. Both men and women reported having sexual dysfunctions due to Parkinson disease, but the effects

were individual. Variation in the other symptoms of PD among patients was reported as well by the studies (Sjödahl et al. 2018:1; Twomey et al. 2018:301), which indicates the importance of holistic patient-centred care.

The results highlighted the importance of healthcare professionals' support for PD patients. Simultaneously, however, the incompetency of healthcare professionals was mentioned by several studies (McClurg et al. 2016:4; Nazzal & Khalil 2017:78; Twomey et al. 2018:305), which had a direct impact on patients' attitudes and their adaptation to Parkinson's disease. Some patients reported that healthcare professionals viewed them more as a burden and did not have enough time for them to go through their condition properly. A focus on motor symptoms, in detriment to patients' non-motor symptoms and psychological well-being, was common among healthcare professionals. Lack of communication between healthcare professionals and patients was also an issue that arose in the study conducted by Nazzal and Khalil (2017:78), which often resulted in the delayed acceptance of the diagnosis and seeking to find alternative solutions from folk remedies.

The results of our thesis showed that the non-motor symptoms of PD had a major impact on the health-related quality of life of patients. Non-motor symptoms such as mood, apathy, sleep problems, fatigue, depression, cognitive impairment, bowel dysfunctions and drooling made patients feel ashamed and bitter. This also led them to develop suicidal thoughts and was associated with social isolation. (Den Oudsten et al. 2011:2495–2597; Gibson & Kierans 2016:540; Haahr et al. 2010:1233; Leavy et al. 2017:86; McClurg et al. 2016:3–6; Sjödahl et al. 2018:4.) Similar findings were also reported by previous studies carried out by Martinez-Martin et al. (2011) and Kadastik-Eerme et al. (2015) where they assessed the effects of non-motor symptoms on the health-related quality of life of people with PD. Martinez-Martin et al. (2011:404) revealed that many of the non-motor symptoms go untreated because the patients did not connect the symptoms to their Parkinson's disease, or they lacked awareness from their healthcare professionals. Attention is required on these non-motor symptoms as it helps in recognizing the symptoms earlier and giving the right treatment. (Kadastik-Eerme et al. (2015:7). This will also help in improving the patient's psychosocial health.

Deep Brain Stimulation (DBS) was regarded as a promising treatment for PD when medications were no longer effective. After undergoing the DBS procedure, participants in

the study carried out by Haahr et al. (2010:1235) had substantial improvements in their activities of daily living and motor symptoms, which promoted their quality of life. However, DBS also caused numerous changes and new symptoms in participants' lives, which they found hard to adjust to. Although DBS was considered by many participants as a sort of "miracle treatment", some participants also reported that their expectations were not met after the procedure and that there were not enough discussions about the downsides of the treatment. The study implicated the importance of understanding the changes and experiences of patients undergoing DBS procedure and continuous support from healthcare professionals after the treatment.

Economic factors were mentioned in only one study done by Den Oudsten et al. (2011:2504), where participants described the importance of having sufficient financial resources, which contributed to their quality of life. People with less financial resources were more limited in participating in any leisure activities. They also stated that financial resources helped them in adapting their home environment to their disabilities. More information regarding this topic is needed as it has a clear impact on the quality of life for people with PD.

## 6.2 Validity

Validity shows trustworthiness and consistency regarding the methodology, sampling process, data analysis and the results of the study (Golafshani 2003:599). The databases we chose to use, CINAHL and MEDLINE, were reliable and credible sources. We also sought help from the informatician of Metropolia UAS with the search terms and search techniques. Although this thesis was not a systematic literature review, we have applied the same methods to collect and analyse the data. We used assessment tools such as JBI and JUFO, to evaluate the quality of our research articles and the journals where they were published. This helped to assess the trustworthiness and relevancy of the selected articles. This whole process ensured that we got academic research articles that were of high quality and relevant to our research questions.

A researcher must ensure the reliability and validity of a study by avoiding being bias and maintaining trustworthiness (Golafshani 2003: 599). We tried to avoid this issue by going through the research articles independently and discussing the emerged dissimilarities in the selection and analysis of the research articles. The validity of research is



increased, when the process of analysing the data is conducted by more than one person (Stolt et al. 2015: 94). All our selected articles were qualitative studies and used interviews as the method of collecting data. The findings of our thesis answered our study questions and reflected the data as it appeared in the selected articles.

Reliability is increased when there is a clear link between the data and the results. (Elo & Kyngäs 2008:112). Every meaning unit was carefully chosen from the selected articles and were then listed in the content analysis table. Additionally, the process of data collection and analysis was described in detail and with honesty. However, despite our aim to be as consistent and systematic as possible, there is still a possibility that some relevant studies were unintentionally left out. Furthermore, since we had non-English languages as an exclusion criterion, this might have reduced the total hits we got from the data search.

### 6.3 Ethical considerations

As for the ethical considerations, our research is written according to guidelines accepted by the research community which are integrity, accuracy and meticulousness in every part of the research process (The Finnish Advisory Board on Research Integrity 2012.). All sources were acknowledged and respected by citing their publications correctly. No copyright violations were conducted during any process of the thesis. Regarding plagiarism, the Turnitin program was used to assess the originality of our text in the thesis.

The ethical questions in literature reviews are related to research questions and adhering to the ethical guidelines during the whole process of the review (Kangasniemi et al. 2013:292). As this thesis was conducted as a descriptive literature review, there was no need to get a permit to initiate the thesis. Thus, the ethical considerations regarding confidentiality and consent were not relevant in this work since we were not dealing with sensitive and personal data of individual people.

### 6.4 Conclusion and suggestions for future studies

The results underlined that non-motor symptoms of Parkinson's disease had a more profound effect on the health-related quality of life than motor symptoms due to lack of awareness from both healthcare professionals and patients. A holistic patient-centred

approach is needed in care as Parkinson's disease affects patients individually. Additionally, there are physical, psychological, social and economic factors that help to promote the quality of life for patients with Parkinson's disease along with Deep Brain Stimulation.

Based on our findings, a gap in the knowledge was identified on how economic factors affect the quality of life of patients with Parkinson's disease. Future studies could be conducted on this topic as economic factors have a major impact on the quality of life. Another topic of interest that might help to develop the care directed to these patients would be charting healthcare professionals' attitudes and experiences of treating non-motor symptoms of Parkinson's disease.

The results of this thesis supported the previous studies about the wide range of motor and non-motor symptoms of PD and their impact on patients' quality of life. Additionally, healthcare professionals' inexperience of treatment of Parkinson's symptoms were noticed throughout the analysis of the selected studies. This implicates the need for additional educational programs for healthcare professionals to treat patients in a holistic manner. Although none of the selected studies were conducted in Finland, other Nordic countries such as Sweden and Denmark were well represented among the selected studies (n=4/11). Since the health care systems of the Nordic countries are highly similar, it is likely that the findings of this thesis can also be applied to the Finnish healthcare system.

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Table 5. Framework for analysing research articles (n =11)

| Author(s), year, country  | Purpose   | Data collection and analysis method                                 | Number of participants | Main results  | JBI   |
|---|---|---|------------------------|---|-------|
| Den Oudsten, B. L., Lucas-Carrasco, R., Green, A. & Whoqol-Dis Group. (2011) UK & Ireland (1) | To identify factors that persons perceive as particularly important for QOL.  | -Qualitative study<br><br>-Group interviews                         | n=38                   | New themes were identified in the study, which were practical adaptations to PD, personal adaptations to PD, the ability to communicate and the availability of communication supports. The study found out that PD affects QoL significantly in physical, psychological, social and environmental ways.  | 9/10  |
| Gibson, G. & Kierans, C. (2016), UK (2)   | To explore the lived experience of older men with PD in context of aging and masculinity                                    | -Qualitative study<br><br>-Narrative and semi-structured interviews | n=15                   | Ageing process together with gender influences on how men coped with the experiences of living with PD. The study suggests that PD has a negative impact on men's visceral embodiment (basic movements of the body and intimate functions), pragmatic masculine embodiment (i.e. the use of body for traditional masculine occupations and activities) and experiential embodiment (changes in sensations, emotions and feelings towards their own body).   | 8/10  |
| Haahr, A., Kirkevold, M., Hall, E.O. & Østergaard, K. (2010) Denmark (3)                      | To explore and describe the experience of living with PD when treated with Deep Brain Stimulation (DBS)                     | -Qualitative study<br><br>-In-depth interviews                      | n=9                    | DBS had a profound positive impact on participants' body functions but it also caused changes in body image and new symptoms among participants. Participants went through three adjustment stages after the DBS procedure, which were "being liberated"(rejoicing about the positive changes and gaining hopeful attitude), "changes as a challenge" (facing the challenges of changed body and loss of control with medications and with the right electric stimulations) and "reconciliation" (redefining life regarding living with PD) | 9/10  |
| Leavy, B., Skavberg Roaldsen, K., Nylund, K., Hagströmer, M. & Franzen E. (2017) Sweden (4)   | To explore and describe perceptions of a highly challenging balance training program among people with mild to moderate PD. | -Qualitative study<br><br>-Face-to-face in-depth interviews.        | n=13                   | Physical exercise was considered and used as both short-term and long-term strategy to slow down and counteract the progression of PD. Participation in the balance training program helped the participants to re-evaluate their physical and cognitive capabilities. Major hindrance to participation were non-motor symptoms of PD such as apathy  | 10/10 |

|   |  |   |      |  |      |
|---|--|---|------|--|------|
|   |  |   |      | and general deterioration of their health. The study suggests that early prescription of physical activity to newly diagnosed people along with continuous support are essential for the maintenance of quality of life.   |      |
| McClurg, D., Walker, K., Aitchison, P., Jamieson, K., Dickinson, L., Paul, L., Hagen, S. & Cunningham, A.-L. (2016), UK (5) | To explore the experiences of PD patients who suffer from constipation, the impact this has on their lives, and the effect of using lifestyle changes and abdominal massage as a form of constipation management | -Qualitative study<br><br>-Semi-structured interviews               | n=14 | Constipation was the main bowel problem among the participants and it affected their social, emotional and psychological wellbeing. This was also linked to decreased quality of life. Abdominal massage was reported to be effective and a pleasant method against constipation by majority of the intervention group (n=4/7).  | 9/10 |
| Nazzal, M. S. & Khalil, H. (2017) Jordan (6)  | To describe the daily living experiences and impact on lives of Jordanian individuals with PD  | -Qualitative study<br><br>-Semi-structured interviews.              | n=8  | Stigma, mixed emotions and experience of decreased autonomy and difficulty in performance of ADL were reported by participants affected by PD. Early acceptance of the disease and interventions, spiritualism along with family support were key adaptation methods mentioned by participants.  | 9/10 |
| Sjödahl Hammarlund, C., Westegren, A., Åström, I., Edberg, A. & Haggell, P. (2018) Sweden (7)                               | To explore the impact of living with Parkinson's disease   | -Qualitative study<br><br>-Face-to-face semi-structured interviews  | n=19 | The study found four major subjects, which represented the impact of living with PD, which were "changed prerequisites for managing day-to-day demands", "Loss of identity and dignity", "compromised social participation" and "the use of practical and psychological strategies". The study results point out that a needs-based approach is needed to better understand the impact of PD along with a patient-centered care and interventions. | 8/10 |
| Soleimani, M. A., Bastani, F., Negarandeh, R. & Greysen, R. (2016), Iran (8)  | To explore the primary concerns and perceptions of patients living with Parkinson's disease  | -Qualitative study<br><br>-Semi-structured, face-to-face interviews | n=17 | "Fear of becoming disabled" was deemed as the primary concern of Patients, which affected their physical, social, mental and emotional aspects of their life. The study also found that PD patients face numerous challenges in their self-care. which were caused by progressive physical disability, mental alterations and self-change.   | 9/10 |



|   |   |   |             |   |              |
|---|---|---|-------------|---|--------------|
| <p>Stegmüller, E.L, Hurt, T.R, O'Connor, M.C, Camp, R.D, Green, C.W, Pattee. J.C &amp; Williams, E.K (2017) USA (9)</p> | <p>To obtain participants' views of their involvement in a group singing intervention (GSI) led by credentialed music therapists.</p>   | <p>-Qualitative study<br/><br/>-Interviews</p>                  | <p>n=20</p> | <p>Participants deemed the group singing therapy (GSI) beneficial, enjoyable and engaging, which also improved their physical, mental and social health. Participants experienced improvement in their breathing, swallowing, relaxation and sleeping along with ability to speak louder which facilitated the communication with their close ones.</p>   | <p>10/10</p> |
| <p>Twomey, D., Stuart, S., Baker, K. (2018), UK (10)</p>  | <p>To develop a greater understanding of living with pain and Parkinson's in order to guide healthcare professional's future practice.</p>  | <p>-Qualitative study<br/><br/>-Semi-structured interviews</p>  | <p>n=4</p>  | <p>Psychological impact of pain, social impact of pain and disconnect between the professional and patient were themes that emerged from the interviews. The participants had different coping strategies. Some of these participants had their own way of managing their pain. They felt that the healthcare professional were not of much help when it comes to helping them with ways of coping with the pain.</p> | <p>8/10</p>  |
| <p>Westergren, A., Hagell, P., Wendin, K. &amp; Sjöhdah Hammarlund, C. (2016) Sweden (11)</p>                           | <p>To explore experiences of mealtimes and related tasks among people with PD and to link these to the International Classification of Functioning, Disability and Health (ICF)</p> | <p>-Qualitative study<br/><br/>-Semi-structured interviews.</p> | <p>n=19</p> | <p>The motor symptoms of PD had a negative impact on mealtime situations and mealtime related activities. This incompetence had a direct impact on a patients' body functions, activity, participation and psychosocial factors, which also resulted in decreased emotional wellbeing.</p>  | <p>8/10</p>  |