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Perceived Social Support, Caregiving Appraisal and Quality of Life among Caregivers of Individuals with Parkinson Disease

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Abstract

Parkinson's disease is a neurodegenerative disorder with no cure, and the progressive disease worsens gradually. The caregivers' QOL, support, and caregiving appraisal are essential to ensure the quality of life of individuals with Parkinson's Disease (IWPD). One hundred three caregivers of IWPD involve in this study. The caregivers' QOL was significantly associated with the caregivers' comorbidities, duration of caregiving, living arrangement, the IWPD's gender and comorbidities. Furthermore, their QOL was significantly correlated with the caregiving appraisal. Therefore, it is essential to identify the risk factors, education needs, and caregiving appraisal in developing an intervention program to improve the QOL among caregivers.

Keywords: social support; caregiving appraisal; quality of life; Parkinson's disease.

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1.0 Introduction

Parkinson's disease (PD) is a progressive neurodegenerative disorder that affects roughly 6.3 million people worldwide. It commonly develops and involves the elderly, aged 65 years and above, but recently, the development of 'young onset' PD occurred even before reaching 50. Most individuals with Parkinson's disease (IWPD) in countries will stay at home, so it is crucial to understand the consequences of this caregiving to the caregivers (Baby et al., 2021). Furthermore, more than six million people will be living with PD in Asia by 2030 due to rapid population aging and lifestyle factors (Grün et al., 2016; Tan, 2020)

The disease characteristic such as frequently tremors, muscle rigidity, and slowness of movement as a result of the loss of cells in the brain that produces dopamine, need for assistance, mostly from their family members or caregivers, in terms of medical, emotional, and social support (Greenwell et al., 2015 & Rajiah et al., 2017).

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The role of a caregiver becomes increasingly important with the progression of PD, the severity of motor impairment, and the increasing age of the patient and in managing this long-term care (Dhandapani et al., 2015; Leiknes et al., 2015; Grün et al., 2016 & Rajiah et al., 2017).

The need for social support, especially among the caregivers of the IWPDP, is essential. The lower social support was associated with a higher risk of depression among the caregivers. The potential sources of social networks include immediate and extended family members, friends, community members, and government and non-governmental organizations for the financial, emotional, and relevant information for solving caregiving issues. Therefore, strengthening the social network could be one of the strategies for dealing with the caregivers of the IWPDP (Abu Bakar et al., 2014; Jensen et al., 2014 & Chai et al., 2018).

The caregiving appraisal and the social support closely affected the QOL among the caregivers (Martinez-Martin et al., 2015; Lee et al., 2018). Since the QOL of IWPDP is well studied, the QOL of their caregivers has seldom been investigated. As it is stressful to care for an individual with PD, it was expected that the personal life and QOL of the caregivers would be affected (Demeulemeester et al., 2015; Chu et al., 2019). Therefore investigating dimensions in QOL of caregivers is essential to increase the quality of care provided to the IWPDP.

2.0 Literature Review

Caregivers play an essential role in assisting IWPDP, especially in their activities of daily living (ADLs), medication and medical management, household chores, financial management, transportation, social and emotional support, and decision making regarding medication (Demeulemeester et al., 2015; Shin & Chai, 2019). It is an all-day job, and the complex symptoms of PD increase the care dependency, which consequently changes the caregivers' quality of life (QOL) across the continuum of care (Rodríguez et al., 2015; Zhong et al., 2016; Lee et al., 2019)

Caregiving topics such as caregivers' burden, QOL, physical health, psychological well-being, caregiving appraisal were much debated and have attracted universal attention. (Chuluunbaatar et al., 2016; Pesantes et al., 2017; Anabajo et al., 2018)

Several works have highlighted the negative impact on caregivers' health and health-related QOL. Caregiving for the patients imposes a significant burden on the family directly or indirectly, which results in higher levels of stress and depression; and lower levels of subjective well-being, self-efficacy, and physical health. Studies on families of patients with depression on caregivers' burden showed that caregivers have experienced moderate to severe limitations (Bauer et al., 2015; Olawale et al., 2014; Grün et al., 2016; Chai et al., 2018).

Managing IWPDP requires long-term care and poses a significant burden on caregivers. Caregivers' QOL depends on emotional well-being, level of social support, and the quality of the relationship between IWPDP and their caregivers (Martinez-Martin et al., 2015; Theed et al., 2017; Lee et al., 2018).

Caregivers with lower social support showed poorer QOL. Social support is a significant factor in caregivers' QOL, reducing the caregiving burden and improving the caregiving experience. Moreover, providing rest to caregivers through social support can relieve their burden and stress (Soh et al., 2013; Tanji et al., 2013; Yoon & Tak, 2014; Lee et al., 2018).

Family support, which constitutes a part of social support, is vital to caregivers' self-care, in which strain could lead to more problems of negative caregiving appraisal. Caregivers often regard caring as a duty or responsibility, and based on Asian culture, family members who do not assume the caregiver role may experience feelings of discomfort, such as guilt, due to avoiding the responsibility of patient care (Lageman et al., 2015; Yoon & Tak, 2014; Lee et al., 2018).

3.0 Methodology

A descriptive cross-sectional study design was used to determine the associated factors of the quality of life among caregivers of individuals with Parkinson's disease (IWPDP) by assessing the perceived social support, caregiving assessment, and the demographic characteristic of the caregivers and the IWPDP. The data was collected among 103 caregivers of IWPDP in a neurology specialist clinic in a Tertiary Hospital using a structured and validated questionnaire from June to October 2021. In this study, a family member, such as a spouse, daughter, or son, and any other member who cared for IWPDP, represented caregivers.

The ethical study approval was gained from the institutional organization and the hospital. The researchers explained the purpose and study procedures to respondents and informed them that their involvement in the research was voluntary. The survey took 20–30 minutes to complete. No identifying values could link the data; therefore, anonymity was ensured, and all confidential information is kept.

This study used self-administered questionnaires adapted from the previous research consisting of four sections. First, the sociodemographic characteristics of caregivers included the factors of the caregiver and the IWPDP such as age, gender, race, marital status, employment, educational level, relationship, health expenditure, comorbidities, and duration of caregiving and living arrangement, and the clinical impression of severity index for Parkinson's disease (CISI-PD).

The second section of the questionnaire is the perceived social support (PSS) measured using MSPSS by Zimet et al. (2016), which consists of 12 items that cover three dimensions; family, friends, and significant others. The original study reported a Cronbach's alpha of 0.88.

The following section measured the caregivers' appraisal using the caregiving assessment scale (CAS) by Lawton et al. (2000) with 27 elements and five dimensions based on the combined scale consisting of five subscales, namely, burden (9 items), satisfaction (6 items), mastery (6 items), demand (3 items), and impact (3 items). Five of the scale's 27 articles were evaluated on a 5-point scale

ranging from one = do not agree at all to five = strongly agree. A higher score indicates a more negative appraisal of the caregiving experience. The original study reported a Cronbach's alpha of 0.86.

Lastly, the QOL was measured using PDQ-Carer (Jenkins et al., 2012); which consists of 29 items divided into four subscales: personal and social activities (12 items), anxiety and depression (6 items), self-care (5 items), and strain (five items) (six items). A lower score indicates better QOL; a score of zero represents the highest level of self-reported QOL, while a score of 100 represents the lowest level of self-reported QOL. This scale proposes four dimensions of QOL, which specify the importance and concern of IWPD caregivers. Cronbach's alphas were reported to be 0.94.

The data were analyzed using SPSS version 26.0. The significance level was set at $p < .05$ for the inferential statistic. Descriptive statistics were used to analyze the demographic characteristics, PSS, CAS, and the QoL. Pearson's correlation coefficients were calculated to investigate the relationships between social support, caregiving appraisal, and caregivers' QOL.

4.0 Results

4.1 Demographics Characteristics of the Caregivers and the IWPD

A hundred and three caregivers with a mean age of 50 years old participated in this study. The majority of them were female and married. Most of them were employed and had a good level of education as nearly all had secondary to tertiary levels of education. Almost half of them were Chinese, and most of them were the IWPDs' children and spouses, so most of the caregivers reside with the IWPD. The duration of caregiving was around five years, as early as two months, and the most extended period of care was 18 years. The majority of them were among the group with an income below RM2000 and had comorbidities. The characteristic of the IWPD that been cared for by the respondents, aged between 42 to 93 years old, with the mean age of 70 to 80 years old. More than half of these IWPDs were male, Chinese, married, and not working. They had an excellent academic background as most of them finished their secondary and tertiary level of education. Since Parkinson's disease was diagnosed, their disease duration was between one to 29 years, with a mean of 7.45 years. Most of them had mild to moderate levels of the clinical impression of severity index for Parkinson's disease, and they too had comorbidities.

Table 4.1.1 the characteristics of the caregivers of IWPD (*n*: 103)

Variables	Frequency (n)	Percentage (%)
Age (years-old)		
Mean: 50.30; SD: 14.71		
Min: 21		
Max: 83		
<40	31	30.1
41-60	34	41.7
61-70	22	21.4
>71	7	6.8
Gender		
Male	33	32.0
Female	70	68.0
Ethnic		
Malay	16	15.5
Chinese	53	51.5
Indian	23	22.3
Others	11	10.7
Marital Status		
Single	24	23.3

Married	72	69.9
Divorced / Widowed	7	6.8
Employed		
Yes	60	58.3
No	43	41.7
Level of education		
Primary	2	1.9
Secondary	34	33.0
Tertiary	67	65.1
Relationship with patient		
Spouse	40	39.8
Children	45	43.7
Others	18	16.5
Caregivers health expenditure (RM) / month		
0	3	2.9
<1000	60	58.3
1001-2000	26	25.2
2001-3000	5	4.9
3001-4000	4	3.8
>4000	5	4.9
Comorbidities		
Yes	81	78.6
No	22	21.4
Duration of caregiving		
Mean: 58.81 months; SD: 49.31		
Min: 2 months		
Max: 216 months		
Living Arrangement		
Reside with patient	90	87.4
Reside apart from patient	13	12.6

Table 4.1.2 The characteristics of the IWPD (n: 103)

Variables	Frequency (n)	Percentage (%)
Age (years-old)		
Mean: 70.80; SD: 9.54		
Min: 42		
Max: 93		
41-60	14	13.6
61-70	33	32.0
>71	56	54.4
Gender		
Male	58	56.3
Female	45	43.7
Ethnic		
Malay	15	14.6
Chinese	62	60.2
Indian	24	23.3
Others	2	1.9
Marital Status		
Single	7	6.8
Married	77	74.8
Divorced / Widowed	19	18.4
Employed		
Yes	11	10.7
No	92	89.3
Level of education		
Primary	18	17.5
Secondary	47	45.6
Tertiary	38	36.9
Disease duration since Parkinson's Disease diagnosis (years)		
Mean: 7.45; SD: 5.29		
Min: 1		
Max: 29		
Comorbidities		
Yes	76	73.9

4.2 The Perceived Social Support

Table 4.2 describes the perceived social support reported by the caregivers of the IWPD. The total score of the MDPSS was 64.06 (± 15.60), which indicated that the caregivers of the IWPD had slight perceived social support, and it was supported by the mean score of MDPSS of 5.34 (± 1.30). This study reported that the highest perceived support was from the family (22.66 ± 5.37), followed by the significant others or particular person (22.36 ± 5.24), and lastly from their friends (19.04 ± 7.65). The caregivers strongly agreed that their family tries to help them by sharing their problems.

Table 4.2: The level of Perceived Social Support

	Family	Friend	Others	Total
Total Score (SD)	22.66 (5.37)	19.04 (7.65)	22.36 (5.24)	64.06 (15.60)
Mean (SD)	5.67 (1.34)	4.76 (1.91)	5.59 (1.31)	5.34 (1.30)

4.3 The caregiving appraisal among caregivers of IWPD

Table 4.3 presents the perceptions and the experience of the caregivers of IWPD. The mastery and satisfaction domains depicted positive appraisal, while the perceived burden and environmental impacted domains represented negative appraisal. The average score for caregiving appraisal was 82.34 (± 16.74). The highest mean score, 3.76 (± 0.99), was obtained in the caregiving satisfaction domain, followed by the caregiving mastery domain, 3.38 (± 0.83). In contrast, lower mean scores were recorded for the negative attitude domains of perceived caregiving burden 2.66 (± 0.83) and environmental impact 2.34 (± 0.98).

Table 4.3: Score of caregiving appraisal subscale

Subscale of Item	Total Range	Mean/SD	Standard Score Range	Mean / SD
Burden	9-45	23.96 (7.50)	1-5	2.66 (0.83)
Satisfaction	6-30	22.58 (5.95)	1-5	3.76 (0.99)
Mastery	6-30	20.27 (5.01)	1-5	3.38 (0.83)
Impact	3-15	7.03 (2.95)	1-5	2.34 (0.98)
Demand	3-15	8.50 (2.49)	1-5	2.83 (0.83)
Caregiving Appraisal	27-135	82.34 (16.74)	1-5	3.05 (0.62)

4.4 The Caregivers' Quality of Life

Table 4.4 describes the caregiver's QOL. A lower score indicates higher QOL; a score of zero represents the best level of self-reported QOL, whereas a score of 100 represents the poorest level of self-reported QOL. This scale suggests four dimensions of QOL, which specify salience and concern of caregivers of IWPD (Jenkinson et al., 2012)

This study revealed that the caregivers' QOL score was 46.54 (± 23.24). The highest score on the caregiver QOL was "strain" with a mean of 41.26 (SD: 23.14), followed by "anxiety and depression" (39.81; ± 27.84). While the lowest score was "self-care" (31.55; ± 25.32) and "personal and social activities" (34.63; ± 25.77).

Table 4.4: Score of caregiver quality of life subscale

Subscale of Item	Mean	SD
Personal and social activities	34.63	25.77
Anxiety and depression	39.81	27.84
Self-care	31.55	25.32
Strain	41.26	23.14
Caregiver quality of life	36.54	23.24

4.5 The association between the sociodemographic characteristic with the QOL among caregivers of IWPD

This study revealed significant differences in the caregivers' QOL according to the following variables: the caregivers' health expenditure, comorbidities, duration of caregiving, and living arrangement with a p -value less than 0.05.

There were associations between the sociodemographic characteristic of the IWPDP with the QOL among caregivers. Gender and the commodities of the IWPDP are significantly associated with the QOL among the caregivers, with the *p*-value less than 0.05.

4.6 Relationship between caregivers' QOL with caregiving appraisal and perceived social support.

Table 4.6 showed the relationship between the caregiver's QOL with the perceived social support and the caregiving appraisal. The caregiver's QOL was related to the caregiving appraisal with a significant coefficient of ($r=0.44, p=0.01$). The magnitude of coefficient (*r*) with a value of more than 0.44 indicates a moderate positive relationship. However, there was no significant relationship between the caregiver's QOL and perceived social support; and the perceived social support and the caregiving appraisal.

Table 4.6 Pearson's correlation coefficients of caregiver's quality of life, perceived social support, and caregiving appraisal.

		Total Perceived Social Support	Total Caregiving Appraisal
Mean QOL	Pearson Correlation (<i>r</i>)	0.11	0.44**
	<i>p</i> -value	0.29	0.01

5.0 Discussion

This study aimed to assess the perceived social support, caregiving assessment, and QOL among caregivers of IWPDP. In this study, the caregivers perceived slight social support. The support might be due to the high burden that has been experienced by them, as reported in this study. In addition, the impact of negative appraisal during the caregiving situation threatens their physical, psychological, emotional, and functional health that, leads to this perception, which several studies have concluded (Casado et al., 2018; Kim et al., 2012). Caregivers themselves need support when facing the additional concurrent stress of significant role transitions and the responsibilities of managing IWPDPs' needs, commonly resulting in caregivers' burden. Social support is an essential element for caregivers to reduce depressive symptoms over time. This current study revealed that the most social support obtained by the caregivers was from the family and the particular person in their life. They were convinced that their family tried to help them share their problems with their family members and friends. This was supported by Leung et al., 2020 who reported that the sources of support were an essential dimension of social support, and family and friends are two of the most prominent sources of social support. The literature has consistently shown that support from friends was a protective factor which was based on the few studies reporting support from family and friends in caregivers of patients (Leung et al., 2020; Han et al., 2017; Kahriman et al., 2015)

Another aspect of this study was the caregiving appraisal that encompassed caregiving burden, satisfaction, mastery, demand, and impact. This current study reported that the caregivers' perceived that their privacy, relationship with other family members, and social activities were occasionally affected during their care to the IWPDP. They also felt that their emotional distress experienced sometimes raised from the effect of caregiving on the IWPDPs' physical, psychological, and social life. This might be due to the time spent taking care of the IWPDP caused by the caregivers' lack of time for themselves might lead to unexpected psychological problems such as emotional strain, feelings of guilt, and a sense of defeat. Similar findings were reported by Lee et al. (2018) and Abendroth, Lutz, & Young (2012). IWPDP experience a functional decline that leads to the limitation of independent daily activities, leading to their dependence on family members or caregivers (Lee et al., 2015; Zhong et al., 2016).

However, these caregivers often had positive feelings such as pleasure, affirmation, or joy resulting from caregiving as support. Most of the caregivers in this current study were among the children and the spouse as they regard caring as a duty or responsibility. This statement can be further supported by several studies conducted in Korea (Lee et al., 2018; Yoon & Tak, 2014).

The QOL among the caregivers is essential in providing better care to patients, especially the IWPDP. Caregivers' QOL depends on emotional well-being, level of social support, and the quality of the relationship (Martinez-Martin et al., 2015; Peters et al., 2011). In this current study, most caregivers were mentally strained while caring for the IWPDP. As a result, some of them experienced psychological symptoms such as anxiety and depression. The clinical characteristics of PD, such as functional decline, lead to physical and emotional complaints among caregivers. An increase in the functional dependency due to physical disabilities of IWPDP adversely affects caregivers' QOL (Rodríguez-Violante et al., 2015; Tanji et al., 2013; Zhong et al., 2016).

This study revealed that the caregivers could still properly do some self-care, including personal and social activities. This might be due to the strong support from family and friends in taking care of the IWPDP. Social support is a significant factor in caregivers' QOL. It can reduce the caregiving burden and improve the caregiving experience. Moreover, providing rest to caregivers through social support can relieve their burden and stress (Lee et al., 2018; Yoon & Tak, 2014).

Another finding of this study was the statistically significant differences in the caregivers' QOL with the following variables: the caregivers' health expenditure, comorbidities, duration of caregiving, and living arrangement with a *p*-value less than 0.05. There was a statistical association between the sociodemographic characteristic of the IWPDP with the QOL among caregivers. Gender and the commodities of the IWPDP are significantly associated with the QOL among the caregivers, with the *p*-value less than 0.05. This was supported by several studies that revealed that comorbidities influence IWPDP's cognitive functions, which makes caregiving more difficult (Lee et al., 2018; Vardy et al., 2015). The caregivers' QOL deteriorates when IWPDP have comorbidities or physical disabilities due to the progression of PD (Lee et al., 2018; Rodríguez-Violante et al., 2015; Tanji et al., 2013). The duration of PD had a significant influence on caregivers' QOL, which is in line with previous studies, where our study found that the longer the duration of PD, the lower the QOL of caregivers (Lee et al., 2018; Morley et al., 2012; Razali et al., 2011).

There was a moderate positive relationship found between caregiver's QOL with the caregiving appraisal with the coefficient of significant ($r=0.44$, $p=0.01$) and supported by studies showed that caregiving appraisal consistently related to the QOL (Lageman et al., 2015; Morley et al., 2012; Lee et al., 2018).

6.0 Conclusion

Caregiving appraisal and social support were essential in the caregivers' QOL, which means a lot to the quality of care among the IWPDP, especially those with mild to the moderate index for Parkinson's disease; comorbidities, and need a long duration of care. The support and a sense of responsibility from family and particular persons greatly influence the caregivers' satisfaction. In addition, their mastery of caregiving will help reduce the burden and the impact of caregiving. The importance of identifying the high-risk caregivers, the social support and caregiving appraisal of caregivers of IWPDP, and developing a customized intervention program to improve their QOL. Therefore, further studies can be made in various settings that could focus more on patients with higher severity of Parkinson's disease. This study was limited to a single tertiary hospital, resulting in limited generalizability.

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