



# Positive Experience of Parkinson's Disease Family Caregivers and why is this Significant in COVID Times?

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## Abstract

**BACKGROUND:** The importance of quality informal care and support for those with long-term conditions such as Parkinson's disease is vital particularly during the COVID pandemic. Enhancing the positive aspects of caring is invaluable to support caregivers morale and in managing health system costs.

**AIM:** This narrative review explores the literature related to positive experiences perceived by the family caregiver of a person with Parkinson's Disease in the home setting.

**METHOD:** Studies were selected from seven electronic databases. Studies were selected from seven electronic databases using the systematic search strategy and appropriate search terms. Joanna Briggs Institute critical appraisal tools were used to assess the quality of the studies.

**RESULTS:** From 2049 studies identified, 18 studies were found. Five themes emerged: personal benefits and accomplishments, the quality of caregivers' dyadic relationship, the gratitude experienced, increased family cohesion, and the deepening of caregivers' spiritual experience.

**CONCLUSION:** These findings will enable development of more appropriate plans and support from health-care systems to enhance the positive experiences of voluntary home caregivers and reduce overall costs.

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## Introduction

Parkinson's disease is the second most common neurodegenerative disease after Alzheimer's disease, with around 10 million people living with Parkinson's disease globally [1]. The motor symptoms, including tremors, bradykinesia, rigidity, imbalance, and various non-motor symptoms such as sleep and mood disorders, mean that people with Parkinson's Disease (PwPD) experience many restrictions in their daily activities [2], [3]. As a result, family members often become informal caregivers who provide extensive, uncompensated, physical, emotional, social, and financial support [4]. This was evidenced by the study of Carrilho *et al.* which showed that caregiver of PwPD reported 72% burden (48% mild, 19% moderate, and 5% severe) [5]. Providing care for PwPD is challenging, especially since the disease is known as a long-term neurodegenerative disease with no current cure [4], [6].

Consequently, this creates more dependency of PwPD's on their family caregivers [3], [4]. This increased demand for day-to-day caregiving activities to support PwPD can also lead to physical and psychological health problems and financial strain for the caregivers if they are not well-supported [6], [7], [8], [9]. Moreover, the pandemic of COVID-19 has been devastating for vulnerable populations and their caregivers [10]. Rigorous rules, social distancing and lock down may have also it more difficult for them to provide care to PwPD [11].

Most research involving PwPD caregivers has focused on negative experiences when caring for PwPD, often describing these as the burden of care [6], [12], [13]. Sometimes, the caregiving experience is discussed in a binary perspective or a positive-to-negative continuum. In these descriptions, the positive and negative are often interrelated, closely connected, and in these situations, the positive experiences are inseparable from the negative ones described [14], [15]. This means

the distinctly positive experiences that the caregivers perceive tend to get ignored. There is little attention in the literature to show how caregivers perceived valuable aspects of their caregiver role and how they use this to accommodate and cope as their roles intensify in their caregiving with the progression of the disease in PwPD [16], [17]. This limits the understanding of the whole process of how the caregiver may use positive experiences to adapt and sustain themselves, to the increasing "burden of care" while providing services to PwPD. Therefore, the purpose of this narrative literature review is to synthesise the latest findings of the valuable experience of family caregivers to explore how these experiences have helped them get through while they look after PwPD in the home setting. This will enable the development of more appropriate plans and support from health-care systems to enhance the positive experiences of voluntary home caregivers and reduce overall costs.

The research questions are:

1. What positive experience do family caregivers for PwPD perceive during their caregiving activities?
2. What variables are associated with the positive experience?

Of particular interest are studies focusing on informal (i.e., voluntary) caregivers, especially family caregivers, within the home setting. This review then highlights opportunities for the future practice and research on how positive care experiences can be used to support voluntary caregivers in the COVID-19 pandemic era.

## Materials and Methods

The narrative review method was chosen as described by Ferrari [18]. Narrative reviews aim to identify and summarize what previously published studies have found, avoid duplication, and seek new areas of research that have not been addressed [18]. This review process follows a rigorous document selection and interpretation of narrative procedures from qualitative and quantitative studies. To ensure a structured approach was taken, the review was based on the Preferred, Reporting Item of Systematic Review and Meta-Analyses (PRISMA) [19] guidelines, as illustrated in Figure 1.

### Search strategies

With the help of a health subject librarian, a search for the relevant literature was conducted through seven databases (CINAHL, Medline, Scopus, APA Psych, ProQuest, PubMed, and EMBASE). The key

search terms used were "carer" OR caregiv\* OR "care giv\*" AND Parkinson\* AND benefit OR advantag\* OR positive OR gain OR reward OR uplift OR enjoyment OR pleasure OR gratification OR "care\* satisfaction" OR "satisfaction with care\*". Identical search terms were used in all the databases. Medical subject headings were used for PubMed and MEDLINE. Article publication time was limited to August 2020.

### Inclusion and exclusion criteria

The inclusion criteria were: All studies that reported positive experiences of caregivers of PwPD at all stages of Parkinson's disease; all levels of kinship of careers; only English full-text studies. The exclusion criteria: PwPD not in a home setting; caregivers being paid; positive experiences resulting from being in a specific program or intervention for Parkinson's disease.

## Search results

Following the removal of duplicate studies, 1847 articles were identified. Titles and abstracts were reviewed, which left 182 suitable studies. Full texts of these studies were scrutinized using the above inclusion and exclusion criteria, and 18 studies remained (Figure 1).

### Quality assessment

The evaluation of the suitability and reliability of the selected articles was performed following the Joanna Briggs Institute Critical Appraisal tools [20]. These checklists assess various quality aspects, including the clarity of the research questions, subject recruitment, appropriate methodology and methods, accuracy of results, implications, and reliability of research results. Two authors (CW-C and CE) independently assessed the selected articles and made the final decision. Initial agreement was reached for 80% of the evaluated articles. Discussion among the reviewers resolved any differences in scoring.

### Data extraction and synthesis

To provide a synopsis of the studies, data were extracted by author MS and placed in a table using the following headings: Author/year/country, research design, aims, caregiver characteristics, data collection method/measurement, and findings. The quality ratings were added later. To ensure accuracy, author BL cross-checked the extracted data with the full text of each study.

After selecting the articles, a synthesis of the articles was carried out by authors MS and BL. The first

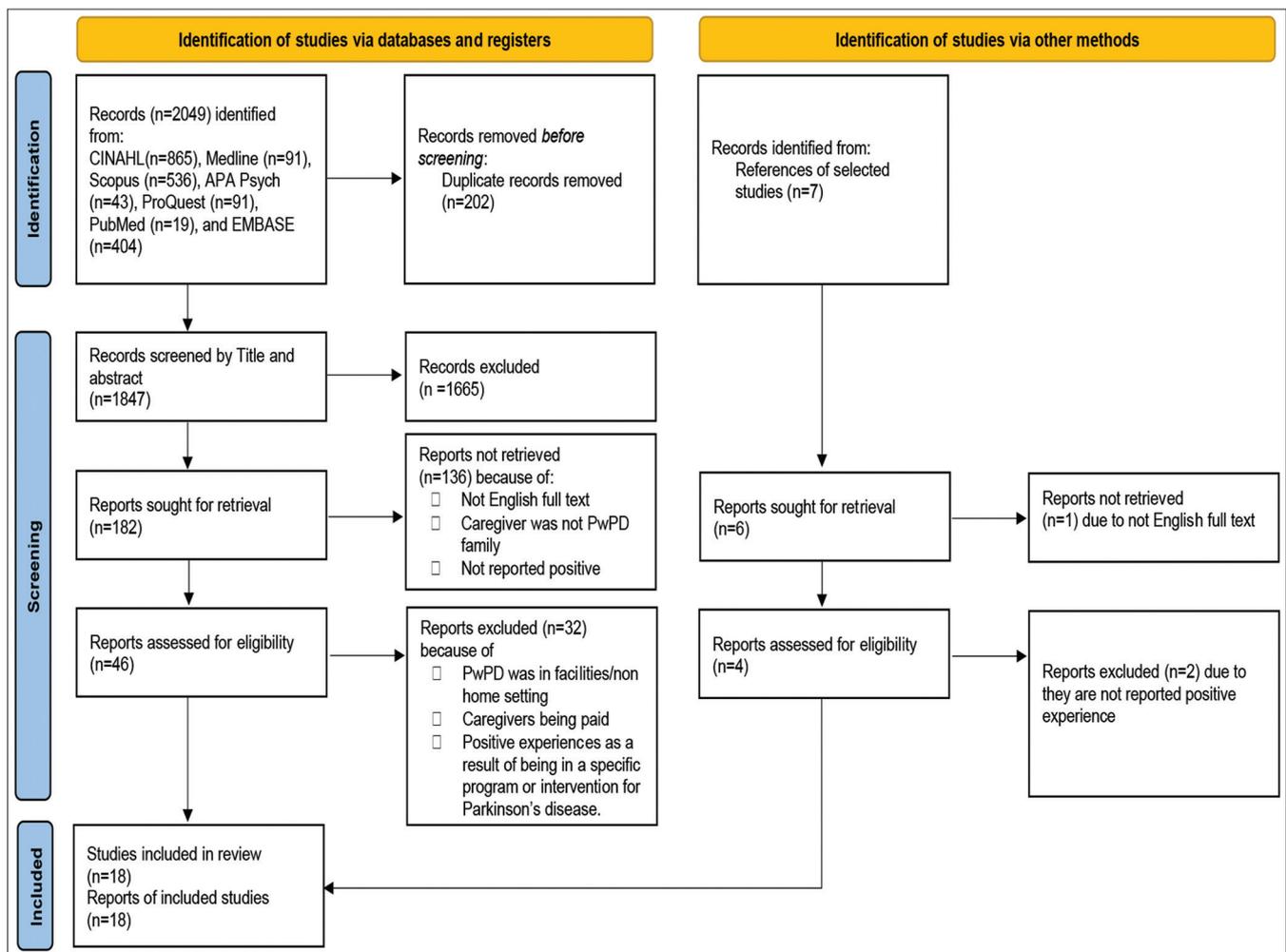


Figure 1: Screening and identification of studies. Adapted from Page et al. The PRISMA 2020 statement: An updated guideline for reporting systematic reviews. *BMJ*. 2021;372:n71

step was identifying and collecting all the different terms for summarizing. Following this, the cumulated findings of the various studies were integrated into domains. In the final step, all domains were then brought together

for evaluation by all authors to ensure that the data obtained were consistent with the domains selected. In this manner, a synthesis of the findings from the selected studies was generated, and the thematic analysis of the literature was developed [21].



Figure 2: Themes of positive experience

## Results

### Country of origin

The reviewed studies were conducted in the USA (n = 8), United Kingdom (n = 1), Canada (n = 1), Spain (n = 1), Indonesia (n = 1), Sweden (n = 2), New Zealand (n = 1), and Singapore (n = 1). Ten studies used a quantitative approach and six used a qualitative approach.

### Caregiver details

In the included studies, the caregivers were mainly partners [14], [16], [17], [22], [23],

[24], [25], [26], [27], [28], [29], [30], [31], [32], [33], [34], [35]. Four articles involved extended family or friends [25], [26], [28], [31] and only one specifically targeted adult children caregivers [15]. Not all studies clearly described the other characteristics of caregivers (Table 1). However, in the studies that included age, the reported ages ranged from 27 to 90 years [29]. As reported in many studies on caregivers, male caregivers were the minority in the studies, with the participation of male caregivers reported being primary caregivers between 10% and 17% [15], [28]. Ethnicity was reported in eight out of 18 studies with Caucasian as the most predominant ethnicity (53–100%) [22], [23], [24], [25], [26], [29], [32], [33], Asian/Pacific Islander as the lowest percentage at 1% [31] and two studies [14], [28] examined only Asian participants. The caring time was found in three studies, with the longest time reported as 24 h per day [24], [25], [34]. In addition to taking care of PwPD, one study said that caregivers were still taking care of their children (under 18 years old) who lived at home with caregivers and the PwPD [27]. Moreover, these caregivers also had poor health [16].

### **Identified themes for the positive experience domain (Figure 2)**

The following themes were identified from the analysis and synthesis of the data.

1. Personal benefits and accomplishments
2. The dyadic relationship quality of caregiving
3. Gratitude
4. Family cohesion
5. Spiritual experience.

#### **Personal benefits and accomplishments**

When people care for PwPD for a long time, several studies report that caregivers gradually gain value from what they do, at least for themselves. Participants believed that self-benefits and feelings of accomplishment were meaningful and positive experiences were gained from their caregiving activities [17], [24], [28]. In a New Zealand study [25], positive aspects were felt by caregivers ( $n = 96$ ) of PwPD, irrespective of their type of Parkinson's – Mild cognitive impairment (PD-MCI), Parkinson's disease dementia (PDD), and Parkinson's disease with normal cognition. These categories showed no statistical difference [25]. Konstam *et al.*, 2003, explored the day-to-day experience of caregivers by asking the question, "Caregiving makes me feel good that I'm helping" using a Likert scale [16]. In this USA study on 58 family caregivers, they found positive meanings in the personal journeys of the caregivers who found the caregiving experience meaningful. This finding is significant because it was also inversely related to the caregivers' depression levels and therefore linked to enhancing caregivers mental health [16].

In other studies, measurements of personal benefits experienced during caregiving are defined as finding something good coming out in a bad situation. It is reflected in the statement from one participant "life is not a race, it is a journey to be enjoyed. Moreover, I think that it slows you down a little bit, but I think you enjoy the journey a lot more, too" [31]. Moreover, one caregiver admitted that her husband's illness contributed to her writing career, even earning money for her daily needs, as she said, "I feel like I've accomplished something and so I feel better about myself" [33]. The caregivers also reported positive life changes resulting from the struggle to cope with their challenging life events or negative experiences [17], [29]. Both caregivers and care recipients' perspectives were given and showed that the caregiver benefit finding scores were slightly higher; score 17–85, with higher scores indicating greater perceived benefit [36]. Their median benefit finding scores in the two studies were 43.1 and 44.2 [17], [29], respectively, compared to the recipients mean score of 42.5 in one study [17]. Furthermore, caregivers' benefit findings positively correlate with the spouses' marital quality ( $p = 0.04$ ) [17].

Based on a study by Tan *et al.*, 2012, most participants reported life satisfaction as a positive aspect of their caregiving. About 80% of caregivers who were women admitted that caregiving gave them satisfaction [28]. Similarly, Mavandadi *et al.*, 2014, found that caregivers' life satisfaction was better than patients with a mean of 23, 9 and 21.3, respectively. Life satisfaction was also significantly related to the caregiver perception of marital quality ( $p = 0.02$ ) [17].

The study based in England by Vatter *et al.*, 2020, on the partners of people with PD-MCI, PDD and dementia lewy body showed that 75% of participants had a high score on the brief resilience scale. This score indicates good resilience in caregiving and an excellent ability to deal with difficult situations. This study also reported those caregivers could positively adapt to changes in their social situations [24].

In the United States, the study of 15 caregivers reported that they receiving reciprocal benefits in their caregiving experiences, such as having the space to focus on what was important in their lives and gaining more appreciation of life [31]. Those caregivers who participated in social and physical activity clubs or care programs acknowledged the positives gained by having a social perspective. They felt that they had found another community that shared similar objectives to support the care recipients [32].

#### **The dyadic relationship quality of caregiving**

The quality of a caregiving relationship is defined as the relationship level between the caregiver and care recipient [37]. This theme was chosen to indicate the quality of marriage, mutuality, and quality of relationships reported in the selected articles.

Mutuality is interpreted as the degree of care, affection, intimacy, mutual concern, and overall relationship satisfaction experienced by those involved [38]. Five articles identified this term as a positive aspect of caregiving [22], [23], [26], [27], [30]. Statistical analysis showed no differences between the mutuality score for caregivers and those receiving care [23]. This suggests the same perceptions of mutual concern and intimacy from the relationship between the caregiver and the care recipient. The caregivers' mutuality score also did not decrease statistically over time [26] while the PwPD condition was stable. However, the mutuality score was lower at stage four or five of Parkinson's disease, based on the Hoehn and Yahr scale than Stage 2 [30]. Carter *et al.*, 2010, explored whether caregiver mutuality was correlated to the caregiver's age, but they did not find it was [27]. A study in the USA (n = 91) found that caregiver mutuality was significantly related to three factors: The recipient's functional ability ( $p = 0.026$ ), time spent on care ( $p = 0.028$ ), and depressive symptoms of the caregiver ( $p = 0.010$ ) [26]. Meanwhile, Karlstedt *et al.* 2019, found that caregiver mutuality decreased with cognitive decline in patients [22].

Mavandadi *et al.*, 2014, found that greater marital quality in the relationships between PwPD and their partners was associated with greater perceived benefits through actor-partner modeling and adjusting the other covariates. Actor-partner modeling allows us to evaluate the relationship between marital quality and benefit finding by looking at caregivers and care recipients as individual clusters [17]. Quality of marriage was also found on 71.2% of caregivers to be higher than the average, which indicated their relationship satisfaction [34]. Two studies [24], [35] examined caregiver-care recipient relationship, which was not only limited to a marriage, reported on approximately 40% of caregivers.

### **Gratitude**

In the literature, some studies showed that adult children often care for their sick parents to demonstrate the gratitude they have felt towards their parents. Two selected articles explored how adult children cared for PwPD [14], [15]. In their study, Habermann *et al.*, 2013 explained that many caregivers appreciate the opportunity to be present and take care of their parents as an expression of their gratitude to the care recipient [15]. Similarly, in the Indonesian study, participants stated that they would care for their parents until they died as evidence of their feeling of filial piety. Moreover, they thanked God that their parents were still with them and tried to make the care recipients happy as long as they could [14]. Caregivers also stated that they enjoyed spending time with their parents despite the challenging and stressful caregiving situations, such as leaving their jobs or even living apart from their spouses to care for their parents [14], [15].

### **Family cohesion**

The scope of benefits of caregiving in the study by Tan *et al.*, 2012, also included strengthening family bonds [28]. Similarly, the studies in the USA by Habermann *et al.* reported that the caregivers also experienced a deepening of their family relationship due to the daily routines of caregiving where family members spend time together more frequently than in pre-caregiving of the PwPD [15], [33]. The intimacy they experienced grew with the time that they were together, as stated: "So, it was a very difficult time, but in the end, it's been positive. The barriers have been broken down, and we are closer" [33].

### **Spiritual experiences**

Although caring for PwPD carries many burdens, one study in Indonesia reported that caregiving activity developed caregiver's spiritual experiences [14]. Caregivers also claimed that this activity was a form of a test of their faith, and for some caregivers, it was perceived as a path that must be taken to wipe out their sins.

## **Discussion**

This review provides insights into the positive experiences perceived by PwPD caregivers and their potential benefits that could be helpful in supporting careers during the COVID-19 pandemic. The experience of PwPD family caregivers in home settings leads them to interpret what they have been through during that time. The dyadic relationship, which describes relationship quality was the most frequently identified variable of positive caregiving experiences in the studies reviewed, followed by personal benefits and accomplishments. The other three themes were only mentioned in four articles reviewed. However, none of these studies asked the participants to rank positive experiences of importance. Other positive aspects of caregiving were reported by PwPD's caregivers, which also reported by caregiver of people with dementia. Meanwhile, spiritual experience is an additional theme for positive family caregiver experiences [39].

In this review process, more experience was explored from articles using qualitative methodologies compared to studies using quantitative methodologies. On quantitative articles, none of the studies discussed their definition of positive experience, and mainly focused on item scores and their correlation with other variables such as quality of life [17], [22], [23], [26], [34], [35]. However, one study compared young and old family caregivers to the positive aspects and concluded that more senior family caregivers experienced higher

Table 1: Study characteristics and study outcomes of reviewed articles

Author/Year/ Country	Research design	Aims	Caregiver characteristics	Data collection method/ measurements	Findings	Quality assessments
Carter et al. 1998, USA [30]	Quantitative (CS)	To examine the experience of spouse's caregiving for their spouse with PD To determine whether their experiences differed by disease stage	n=380 Gender: 70% female Ethnicity: 96% Caucasian Employed: 46% Relationship length: x-38 years	Family caregiver inventory Mutuality scale	Mutuality was found in the caregiver at the beginning of the stage of PD Decreased significantly at stage 2 of PD	JBIf for cross-sectional study: Y=6/8 n=2/8
Habermann 2000, USA [33]	Qualitative (DP)	To explore the challenges faced by middle-aged spouses and the coping strategies	n=8 Caucasian caregiver Gender: 62.5% female Age: 44–58 years. Work: 100% Relationship length: 4 month-30 years	In-depth, semi-structured Interviews	Five caregivers gain positive experience; Two examples were: 1. Caregiver felt accomplished for herself as PwPD illness buffered her publishing career. She published one novel and prepared another one. 2. Caregiver had a better relationship with her husband after a while, struggled with PwPD symptoms, and PwPD got treatment	JBIf for qualitative study: Y=8/10 n=1/10 N/A=1/10
Konstam et al. 2003, USA [16]	Quantitative (CS)	To explore the contribution of finding meaning in general, and finding meaning specifically in caregiving as potentially important explanatory variables in predicting well-being in caregivers of individuals with PD	n=58 Kinship: 89% spouses, 11% daughters Gender: 63.8% female Age: X = 66.6 year, Health condition: 15.3% poor	Finding meaning through caregiving scale The multiple affect adjective check list-R: positive affect	Provisional Meaning related to positive affect and seeking sensation but inversely related to depression There were consistently significant proportions of the variance related to positive affect (PASS) and negative affect (Dys). The purpose was the only significant predictor of PASS	JBIf for cross-sectional study: Y=5/8 n=2/8 U=1/8
Roland et al. 2010, Canada [32]	Qualitative	To present a novel method for exploring caregiver burden and to identify the method by which clinician and family members might work to ameliorate associated problems	n=5 All- spouses female Age: 49–71 years	Probative questions	Caregivers involved in new communities and being a member of some club (social or physical activity club)	JBIf for qualitative study: Y=7/10 n=2/10 U=1/10
Carter et al. 2010, USA [27]	Quantitative (LS)	To compare the differences in the negative aspects of strain and modulators of strain in young and older PD Spouse caregivers	Young spouse: n=31 Age: X = 51.1 years Gender: 61% female Relationship length: 0-25 years Old spouse: n=28 Age: X = 75.71 year Gender: 78% female, Relationship length: 0-45 year 24% of caregivers live with both children (under 18yrs) and PwPD, 36% followed a support group	Positive variables questionnaire; mutuality, preparedness, reward of meaning	A t-test revealed young spouse experienced lower mutuality ( P<0.05), and lower reward of meaning ( P,0.01) with moderate to large effect sizes or 0.54-0.55 and -0.95, respectively	JBIf for cross-sectional study: Y=8/8
Chiong-Rivero et al. 2011, USA [31]	Qualitative	To identify HRQOL domains or themes that reflect patients' perspectives on living with PD in a comprehensive manner.	PwPD=48 n=15 Caregiver Kinship: 8 spouse, 2 children, 5 friend/ others unpaid carer Gender: 86.7% female Age: X = 71.6, Ethnicity: 66.7% Hispanic, 10% Latino, 1% Asian/Pacific islander.	Focus group discussion	Three positive themes that the caregiver gets were: 1. Enhanced sense of appreciation for life and each other. 2. Refocusing on what important in their lives, such as love. 3. Strengthening of their familial relationships	JBIf for qualitative study: Y=8/10 n=1/10 U=1/10
Shim et al. 2011, USA [26]	Quantitative (LS)	To present findings from secondary analysis of longitudinal data on correlates of care relationship mutuality.	n=187 (102 AD, 85 PD). Age: X = 65 year Gender: 73% female Ethnicity: 81% Caucasian and 16% Afro African. Relationship length: 0-25 years	Mutuality scale	Mutuality did not significantly decline over time. Factors related to lower mutuality for these carers were lower functional ability in the care recipient, shorter length of caregiving, and a higher level of depressive symptoms for carers	JBIf for cohort study: Y=9/10 N/A=1/10
Tan et al. 2012, Singapore [28]	Qualitative exploratory	To conduct an in-depth qualitative examination of experiences of Singaporean people caring for those with PD	n=21 Kinship: 14 spouse, two children, five friends/others unpaid carers, 1% were sons Age: 31→71 year Gender: 80% female Ethnicity: 90% Chinese, 10% Indian Access to domestic helper: 61%	Semi structured interviews	Caregivers gain positive emotional outcomes: adaptable positively in a changed social situation, life satisfaction and improved family bond	JBIf for qualitative study: Y=8/10 n=1/10 N/A=1/10

(Contd...)

Table 1: (Continued)

Author/Year/ Country	Research design	Aims	Caregiver characteristics	Data collection method/ measurements	Findings	Quality assessments
Habermann <i>et al.</i> 2013, USA [15]	Qualitative; (DP)	To explore the positive aspects experienced by adult children in providing care to their parent who either has PD or Alzheimer Disease	n=34 (8 PD caregivers, 26 AD caregivers) Age: $\bar{x}$ = 52 years Gender: 82% female Ethnicity: 47% Afro American, 53% Caucasian	In-depth semi-structured interviews	Results indicated that most caregivers had positive experiences. Three relationship-centred themes were identified: spending and enjoying time together, appreciating each other and becoming closer, and giving back care	JB1 for qualitative study: Y=8/10 n=1/10 N/A=1/10
Mavandadi <i>et al.</i> 2014, USA [17]	Quantitative (CS)	To examine the association between perceived benefit finding and marital quality among dyads of individuals with PD and their spouse.	n=50, (25 PwPD and 25 spouse) Age: $\bar{x}$ = 68.04 years Ethnicity: 88% Caucasian Work=48% Relationship length: $\bar{x}$ = 43.3 years	Benefit finding scale Life satisfaction scale Marital quality scale	Benefit Finding score of PwPD=39 Benefit Finding score of spouse=43.1 Benefit finding was significantly associating with the respondent (patients and spouse) who were reporting greater marital quality Life satisfaction score of PwPD=21.3 Life satisfaction score of spouse=23.3 Marital Quality Score of PwPD=30.5, Marital Quality Score of spouse=28.2	JB1 for cross-sectional study: Y=5/8 n=2/8 U=1/8
Navarta-Sanchez <i>et al.</i> 2016, Spain [29]	Quantitative (CS)	To provide a comprehensive analysis of psychosocial adjustment and QoL determinants in PD patients and informal caregivers.	n=174 (91 PwPD and 83 caregivers) Age: $\bar{x}$ = 63 years, range 27–90 Gender: 78.3% female Ethnicity: 88% white Caregiving time: $\bar{x}$ = 6.9 years Work=22.9%	Benefit finding scale	Benefit finding score of PwPD=41.7, Benefit finding score of caregiver=44.2 Finding benefit (personal growth and improvement relationship) was seen as a determinant of a worse psychosocial adjustment Perceiving benefit findings in the disease was also a predictor of worse QoL Age, coping responses, benefit finding, caregiver availability, and resources did not significantly predict the patient's QoL	JB1 for cross-sectional study: Y=7/8 n=1/8
Jones <i>et al.</i> 2017, New Zealand [25]	Quantitative (CS)	To examine caregiver coping strategies and positive aspects of caregiving as potential mediators of the relationship between patient cognitive status and caregiver burden.	n=96 in 3 groups, PDD (15), PD-N (51), PD.MCI (30) Kinship: 82 spouses, 14 children Gender: 80% female Age: $\bar{x}$ = 64.91 years. Caregiving time: $\bar{x}$ = 15.62 h per week	Positive aspect of caregiving scale	The Positive Aspects of Caregiving score were PDN=27.12 PDMCI=27.316 PDD=24.87.	JB1 for cross-sectional study: Y=7/8 n=1/8
Karlstedt <i>et al.</i> 2017, Sweden [23]	Quantitative (LS)	To identify factors associated with mutuality, Health Related Quality of Life (HR QoL) and caregiver burden	n=102 (51 PwPD, and 51 caregiver-spouse) Gender: 56.09% female Age: $\bar{x}$ = 70.07 years. Work=31.4%	Mutuality scale	There was no significant difference between the total scores of the Mutuality Score (MS) in PwPD (med=3.4) and PwPD partners (med=3.1). Regarding dimensions of the MS, only reciprocity (median=3.3 vs. median=2.8, $\square$ = 0.014) was significantly rated more highly by PwPD	JB1 for case series study: Y=8/10 n=2/10
Karlstedt <i>et al.</i> 2019, Sweden [22]	Quantitative (CS)	To examine the role of mutuality as a mediator of HR QoL in the patient who has PD	n=102 (51 PwPD, and 51 caregiver-spouse) n=102 (51 PwPD, and 51 caregiver-spouse) Gender: 56.09% female Age: $\bar{x}$ = 70.07 years. Work=31.4%	Mutuality scale	SEM models, mutuality score was not a mediator of HR QoL (beta. 027; $P$ 0.825). The effect of reduced cognitive function may influence patients' mutuality through partners' mutuality. Worse cognition decreases partners' mutuality, in turn leading to the decreasing level of patients' mutuality	JB1 for cross-sectional study: Y=8/8
Dekawaty <i>et al.</i> 2019, Indonesia [14]	Qualitative; (DP)	To explore family members' experience in caring for relatives with PD	n=5 Kinship: 2 spouses, three children. Age: 31–67 years Work: 80%	Unstructured in-depth interviews	This research found that participants felt spiritual and cultural wisdom in providing care to family members with PD. They expressed a spiritual meaning related to resignation, patience and gratitude, and regarded the situation as a test	JB1 for qualitative study: Y=8/10 n=2/10
Vatter <i>et al.</i> 2020, United Kingdom [24]	Quantitative (CS)	To explore and compare levels of mental health, care burden, and relationship satisfaction among caregiving spouses of people with mild cognitive impairment or dementia in PD	n=136; 87 spouses of PwPD. Gender: 85% female Age: $\bar{x}$ = 69.44 years, Range=48–85 years Work=31.4% Relationship length: $\bar{x}$ = 46.5 years. Range 5–68 years. Caregiving time: max 84 h per week	The family caregiving role The brief resilience scale	As many as 97.06% were satisfied with the role of caring Many spouses in this study had good resilience, emphasizing their ability to cope and adjust to the challenging nature of the care recipients' condition	JB1 for cross-sectional study: Y=6/8 n=2/8

(Contd...)

Table 1: (Continued)

Author/Year/ Country	Research design	Aims	Caregiver characteristics	Data collection method/ measurements	Findings	Quality assessments
Heine et al. 2021, Germany [34]	Quantitative (CS)	To identify factors influencing the relationship satisfaction of PwPD and their caregivers in a cross-sectional observational study	n=79 spouses of PwPD. Gender: 63% female Age: $\bar{x}$ = 62.7 years, Range=37–88 years Work=31.4% Caregiving time: average 5.8 h per day, length 0–24 h per day	Quality of marriage index	The quality of marital index 71.2% of the caregivers reached 34 points or higher with average score was 36.1 points (9.2; min 9; max 45). Regarding the caregivers' gender, a tendency to a reduced relationship satisfaction in male caregivers could be detected even though no significant association could be found after correction for multiple testing. With regard to caregivers' relationship satisfaction, higher HR-QoL of caregivers was significantly associated with higher relationship satisfaction	JBIf for cross-sectional study: Y=8/8
Champagne 2021. USA [35]	Quantitative (CS)	To investigated the associations between responsiveness, as well as perceptions of a partner's responsiveness, and relationship satisfaction for couples coping with PD	n=20 partners of PwPD. Gender: 55% female Age: $\bar{x}$ = 73,97 years, Range=62–88 years Relationship length 7–63 years	Couples satisfaction index	The average care partner's relationship satisfaction was relatively high (M=42.05 out of 51) the higher the score, the higher the satisfaction	JBIf for cross-sectional study: Y=7/8 n=1/8

AD: Alzheimer disease, CS: Cross-sectional, CT: Can't tell, DP: Descriptive phenomenology, JBIf: Joanna briggs institute, LS: Longitudinal study, N: No, N/A: Not applicable, PD: Parkinson's disease, PDD: Parkinson's disease dementia, PDN: Parkinson's disease normally, PD-MCI: Parkinson's disease mild cognitive impairment, PwPD: Person with parkinson's disease, QoL: Quality of life, U: Unclear, Y: Yes.

positive experiences than younger ones [27]. This implies that there are variables that affect caregiving. Nonetheless, the previous studies have shown that these characteristics are not significantly related to the caregiver's quality of life [38].

Family caregivers who perceived their role positively were able to accommodate their challenging caregiving roles, which shaped their resilience and increased their perception of caregiving tasks [16], [17], [24]. The studies also indicated that a positive long-term intimate relationship between the caregiver and care recipient, pre-caregiving could protect caregivers from the stress of their role and support their quality of life [40], [41]. Furthermore, a positive view of caregiving was found helpful for caregivers and encouraged them in their caring role and future [33]. The role performed by family caregivers was found to bring life satisfaction and made them appreciate their life. Moreover, it helped them identify what was essential in their lives, and it also gave them happiness when they discovered they were not alone and many people had the same condition as their care recipient [17], [31], [32]. From this perspective, patient outcomes also influenced the caregiver's perception of mutuality, disease severity, and cognitive impairment [26]. A survey of Chinese family caregivers found the lower caregiver depression was associated with higher mutuality in the hospital or home care settings [42]. However, the length of the relationship between the caregiver and the caregiver may affect mutuality [27].

The spiritual context was revealed by a study based in Indonesia [14]. This explained how in some cultures, individuals, and or families use religion to give context and healing to improve their mental, physical, emotional, and spiritual health while caring for others. A study based in the USA also showed that Indian and Pakistani caregivers use religious places to seek help

when they feel, they have problems with their physical and mental health while caring for their families [43]. Spiritual themes that emerge from the religious context expand the diversity of positive experiences stated by family caregivers [44].

Although two of the qualitative studies reviewed stated that positive experiences were used to help overcome some of the caregivers' problems and stresses, how this was achieved was not clearly explained [14], [15]. The study by Habermann 2000, did explain about coping strategies that caregivers had however, this study did not include positive experiences experienced by caregivers [33]. Nevertheless, the study by Folkman and Moskowitz, 2000, showed a strong correlation between positive attitudes and better coping strategies. Their results illustrated how stressful situations such as caring for someone with a chronic illness can lead to positive adaptations [45].

During avian influenza outbreak on 2009, it is suspected that the H1N1 virus can cause inflammation and degeneration of dopaminergic neurons in the development of Parkinson's disease. This result made PwPD care management more stringent, involving families and carers [46]. As now, we are experience international COVID-19 pandemic, it is impact PwPD and their family caregiver daily care. The involvement in social activities, cognitive, and physiotherapy before COVID could be achieved without facing too many barriers. During the lockdown restrictions, family caregivers have experienced many challenges. Beach et al., 2021 stated that family caregivers experienced higher anxiety and depression, fatigue, sleep disturbances, decreased social participation, lower financial well-being, food insecurity, and increased financial worries [47]. In addition, a variety of PD symptoms have a distinct but significant impact on PwPD and their caregivers when they experience strict home

confinement [11]. Health-care systems should take more responsibility for these unpaid resources given so freely by families who carry such a vast and growing burden for our society [6]. Family caregivers need to be assisted in finding meaning and positive experiences especially as they can only rely on themselves during pandemics like COVID-19 [11], [17].

This review shows that informal and volunteer caregivers are recognized as having an essential role in successfully managing chronic disease at home [6]. However, there needs to be more acknowledgement of these positive experiences and prioritizing their usefulness in maintaining caregivers' well-being and morale to overcome the caregiver burdens identified. A comprehensive assessment of caregivers' needs by those in the prevailing health system would provide the necessary evidence to plan the appropriate services and interventions they need [48]. The early identification and encouragement of positive experiences to prevent or limit the strain of caregiving in the caregiver's experiences of looking after PwPD could be used to target appropriate support programs [16]. This would enable long-term care in the community and prevent premature hospitalization, especially in the current COVID-19 pandemic. Family caregivers could be helped to develop cognitive and behavioral competencies that will make it easier for them to find confidence to continue in their role in caring in the home.

The findings from this review could also be used to generate a paradigm shift from the often-expressed concept of caregiver stress and burden of care to the concept of the positive experience for those caring for PwPD. This paradigm shift to an image of positive caregiving experience would encourage intervention programs that use an empowerment approach and enable personal efficacy for those managing and caring for those with a chronic disease like PwPD [49]. These programs would prompt the caregiver to build up relationships in their dyads. It would encourage caregivers to reflect on the positive benefits they get in their experience of caring for PwPD. In this way, they will have a positive appraisal of their experience of caregiving and the caregiving resources provided for them. This condition may reduce the burden of indirect costs for carers who are then replaced by family caregivers. Based on a study in the UK, the cost of professional carer of PwPD increased to over £27,000 per patient per year [50]. Their unpaid work enables the health system to function more cost-effectively, and sustaining their invaluable role helps prevent escalating costs arising from the COVID-19 pandemic situations in particular and in the health system generally.

### **Limitations of the review**

Within this review, the definition of positive experience was very diverse. Hence, this means a detailed assessment of how positive experience is

measured in the future research is critical. The search was also limited to English publications only. While a robust methodology supported by best practice was used in this review, the possibility of publication and language bias must be acknowledged. This bias was minimized by accessing the grey literature and conducting secondary searches.

## **Conclusions**

Research exploring the positive experiences of caregivers of PwPD has received little attention in the literature. By critically synthesizing the evidence, this review describes the conceptualization and the types of positive experiences of caregivers caring for PwPD. These findings provide a valuable basis to guide future care support programs for those working voluntarily in the community especially in pandemic times. These programs would also provide a basis for further research on intervention programs for family caregivers that favor positive caregiving experiences. COVID-19 has stretched the resources of health-care systems internationally and providing this tailored program support will also help prevent escalating costs in health systems.

### **Disclosure statement**

The views and opinions expressed in this article are those of the authors, and there are no declarations of conflicts of interest.

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