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Depression in partner caregivers of people with neurological conditions; associations with self-compassion and quality of life

Abstract

Objectives: Informal caregivers are vulnerable to poor mental health and quality of life (QoL). Self-compassion may protect against this. This study investigated depression and QoL in partner caregivers of people with a long-term or neurological condition (e.g. dementia or spinal cord injury) and explored the extent to which QoL and self-compassion are predictive of depression.

Design: A cross-sectional, questionnaire design.

Methods: Participants were recruited from charities and support groups. Partner caregivers ($N = 57$) completed assessments of depression, QoL, and self-compassion.

Results: Over half (61.8%) of caregivers experienced at least mild symptoms of depression, illustrating high prevalence among caregivers compared with the general population. Overall QoL was poor compared with non-caregivers. QoL was poorest in the physical domain (M = 51.9, SD = 10.1) and highest in the environmental domain (M = 64.9, SD = 15.8). Both self-compassion and QoL were significant predictors of depression ($p < .05$), explaining 48.8% of the variance. Hours spent providing care was also significantly predictive of depression ($p < .05$).

Conclusion: Self-compassion and QoL may be important targets for supportive interventions for this population. This study underscores the importance of developing supportive interventions for informal partner caregivers, and developing self-compassion in these.

Keywords: compassion; health promotion; caregiver burden; mindfulness; compassion

Introduction

Gradual advances in medical technologies have resulted in people with neurological conditions living longer and requiring care and support of varied degrees over their lifespan. The increase in the frequency of chronic illnesses, specialist care needs, and expensive rates of institutional care have forced over six thousand family members to take up the role of caregiving each year in the UK (Talley & Crews, 2007), indicating that this is an important population to study and support.

The term 'caregiver' refers to an individual who has the responsibility of attending to the day to day needs required for the adequate and comfortable living of another person (Greenwood & Smith, 2015). There is a distinct and clear difference between 'formal and 'informal' caregivers. Formal caregivers receive payment for the services they provide as a caregiver and are required to possess a level of training in care to carry out the role. Informal caregivers are often family members, in this instance spouses, who provide care for their partner in their home and without any pay. Given the lack of training and reimbursement for their care, partner caregivers encounter a host of challenges in their role as a primary caregiver.

From the time of injury or diagnosis of illness, caregivers often find it difficult to accept the diagnosis and often make adjustments in the marital or romantic relationship to accommodate their new role as caregiver (Vitaliano, Zhang & Scanlan, 2003). Further, partner caregivers often experience role overload, lack of education on the illness and the care needs of the recipient, and financial strain due to decreased income (Vitaliano, Zhang & Scanlan, 2003). Such caregiving commitments often involve prolonged hours fulfilling the care-recipient's needs and poor physical and mental health (Tommis, Robinson, Seddon, Woods, Perry & Russell, 2009; Legg, Weir, Langhorne, Smith & Stott, 2013). These can then impede QoL (Farina et al., 2017), thereby highlighting the need to provide adequate support to this group of people and to maintain their own QoL.

Due to the increased demands of caring for someone with a long-term condition, partner caregivers may often ignore their own well-being to avoid feelings of guilt and inadequacy in their role as caregiver (Martin, Gilbert, McEwan & Irons, 2006). Compassion, which has origins based on Buddhist teachings, is an important and fundamental element of the care sector (Wollenburg, 2004), and has the potential to relieve a person's suffering (Kret, 2011). The Dalai Lama (2003, p. 125) explains that:

'For someone to develop genuine compassion towards others, first he or she must have a basis upon which to cultivate compassion, and that basis is the ability to connect to one's own feelings and to care for one's own welfare... Caring for others requires caring for oneself'.

This indicates that compassion towards others can only come best when one demonstrates self-compassion. There are three primary facets which make up self-compassion (Neff, 2003); *self-kindness*, *common humanity,* and *mindfulness*. *Self-kindness* entails being warm and understanding to oneself instead of ignoring pain or punishing oneself with self-criticism. *Common humanity* is the ability to recognize that suffering and personal inadequacy are part of the shared human experience. Lastly, *mindfulness* is about adopting a non-judgemental receptive mind state whereby an individual observes thoughts and feelings as they are. High levels of self-compassion in individuals have been associated with greater psychological well-being and QoL (Neff, 2009). Therefore, encouraging self-compassion in carers will likely aid in promoting positive outcomes on the psychological and mental wellbeing of caregivers as well as those they care for.

The evidence outlined above suggests that maintaining self-care and self-compassion is likely to be of benefit to the general population, and perhaps even more important for those in caregiving roles. This study therefore aimed to explore the QoL of partner caregivers of people with chronic and neurological conditions, and to begin to explore the role that self-compassion might play in managing the wellbeing of this population.

Methods

78 ***Participants***

79 Participants were recruited via carers support groups and through online platforms. Inclusion

80 criteria were: aged 18 years or above (no upper age limit), primary caregiver of a spouse/partner

81 with a chronic and/or neurological illness, assists with most (if not all) of the partner's daily

82 care needs. Caregivers who sought medical attention three months prior to participating in the

83 study, living with a chronic condition before or after the onset of the caregiving role, or

84 showing any cognitive deficit were excluded from this study due to the impact that these could

85 have on QoL. Population norm scores from existing literature (Skevington, Lofty & O'Connell,

86 2003) were used as a comparison group.

87

88 ***Measures***

89   *World Health Organization Quality of Life (WHOQoL-BREF; World Health*

90 *Organisation, 1998):* This 26-item questionnaire measures QoL in four domains (physical

91 health, psychological health, social relationships and environment), graded on a five-point

92 Likert scale. Summed scores range from 0 to 100 with higher scores indicating greater

93 perceived QoL. Cronbach's alpha for the WHOQoL-BREF in the present study was $\alpha = .79$.

94   *Patient Health Questionnaire (PHQ-9; Kroenke, 2001):* Participants rate nine items on

95 a Likert scale ranging from 0 (not at all) to 3 (nearly every day) the extent to which they have

96 experienced mood-related problems within the last 2 weeks. The PHQ-9 incorporates DSM-IV

97 depression criteria and is used as a screening and diagnosis tool, which can also differentiate

98 the severity of depression in individuals with a depressive disorder. In the current study,

99 reliability was good ($\alpha = .88$).

100   *Self-Compassion Scale Short Form (SCS-SF; Raes et al., 2010):* This 12-item tool

101 measures self-compassion in six subscales: self-kindness, self-judgement, common humanity,

102 isolation, mindfulness and over-identification. The SCS demonstrated strong reliability in the

103 present study (α = .90).

104

105 ***Procedure***

106 Data were collected using electronic and/or paper survey questionnaire. Eligible participants

107 were approached with study information via charities and online carers' forums. The study was

108 described and those indicating interest in the study were provided with detailed information. If

109 they consented to taking part, participants were asked to complete a consent form, and the

110 questionnaires.

111

112 ***Analysis***

113 Data collected were analysed using SPSS version 24. Variables were checked for accuracy in

114 entry and for missing data. Two main techniques were used to handle missing data; imputation

115 method and listwise deletion which is the default in SPSS statistical packages. With the

116 imputation method, each missing value was substituted with the mean score and analysis was

117 carried out as if there were no missing values in the data. WHOQOL-BREF raw scored were

118 transformed to a 0-100 scale in line with the stipulated guidelines (WHOQOL-BREF Group,

119 1998). This allowed the scores to be directly comparable with population norm scores from

120 existing literature (Skevington, Lofty & O'Connell, 2004). The level of significance for all

121 analyses was set to less than or equal to .05.

122   Independent-sample t-tests and Pearson's correlation analyses tests were carried out to

123 explore differences between the caregiver sample and population norms on outcome measures.

124 A linear regression was run to explore the extent to which depression could be predicted by

125 self-compassion and QoL.

126

127 *Ethical Considerations*

128 The study was approved by the University of Buckingham School of Science and Medicine

129 Ethics Committee (SSMEC), reference number M34T317. Prior to completing the survey,

130 participants provided consent. Data collection was anonymous, and information provided by

131 participants was non-identifiable.

132

133
134   **Results**

135 *Demographic Characteristics of Caregivers*

136 A total of 57 participants were recruited. Data from $n = 2$ respondents was excluded from the

137 analysis as they were not spouses/partners of the care-recipient. Participants were mostly white

138 British/Caucasian (78.2%) women (74.5%) with a mean age of 58.2 years (SD = 25.5).

139 Participants were mostly married (74.5%), and had been in their current relationships for an

140 average of 25.6 years. Less than 50% were in full- (20.0%), or part-time work (27.3%).

141 Participants spent an average of four hours per day at work, and an average of 8.9 hours

142 providing care (an average of 62.3 hours per week). Further details can be found in table 1.

143

144 *Demographic Characteristics of Care-Recipients*

145 Caregivers were mostly providing care to people with SCI (20%) and Alzheimer's & Dementia

146 (20%). However, 32.7% ($N = 18$) of the caregivers cared for spouses experiencing less common

147 and less represented chronic illnesses (these are shown in table 2).

148

149 ***INSERT TABLE 1 HERE***

150

151 ***INSERT TABLE 2 HERE***

152
153

154 ***Prevalence of Depression***

155 Over half of caregivers experienced at least mild symptoms of depression. Table 3 shows the

156 distribution of PHQ-9 scores according to depression symptom severity. The mean PHQ-9

157 score was 7.91 (SD = 6.33). The larger proportion of carers (68.3%) had minimal to mild levels

158 of depression and 18 caregivers (32.7%) had moderate to severe levels of depression.

159

160 ***INSERT TABLE 3 HERE***

161

162 ***Quality of Life***

163 QoL scores are presented in table 4. Caregivers scores on the WHOQOL-BREF were lower

164 than those of non-caregivers in the UK general population (Skevington, Lofty& O'Connell,

165 2004). Table 4 presents the results of independent samples t-tests, which indicated that scores

166 on all domains were significantly lower in the present sample compared with population norms

167 of previous work (p < .001).

168

169 ***INSERT TABLE 4 HERE***

170

171 ***Relationships Between Demographics, Depression, QoL, and Self-Compassion***

172 Spearman correlations were run to explore relationships between variables (see supplementary

173 information). These indicated that age was significantly positively correlated with hours spent

174 providing care (p < .05), and negatively correlated with hours spent at work (p < .01). Hours

175 spent at work was negatively correlated with hours spent providing care (p < .05), and

176 positively correlated with PHQ-9 scores (p < .01). All domains and total QoL were negatively

177 correlated with depression severity (p < .01) and self-compassion was positively correlated

178 with all QoL domains except physical QoL (p < .05). Self-compassion was also significantly

179 and negatively correlated with PHQ-9 scores (p < .01).

180

181 *Regression*

182 A linear regression was run to predict depression from self-compassion and QoL. The overall

183 regression indicated that the model was a good fit for the data ($F(2, 49) = 23.350, p < .001, R^2$

184 $= .488$), predicting 48.8% of the variance. Both self-compassion ($t = -4.133, p < .001$), and

185 QoL significantly added to the prediction ($t = -3.003, p = .004$).

186   Given the strong correlation, a multiple regression was run to predict depression from

187 between hours spent providing care. The overall regression indicated a good fit for the data

188 ($F(1, 52) = 10.961, p < .05, R^2 = .174$), predicting 17.4% of the variance.

Discussion

The purpose of this study was to investigate the relationships between depression, QoL, and self-compassion in partner caregivers of people with long-term and neurological conditions. Central to this study, over half of caregivers met the diagnostic criteria for depression, with a third of participants demonstrating moderate to severe depression. Similarly, QoL was much lower in all domains for partner caregivers in comparison to the general population. These findings support existing literature on the high prevalence of mental health related illnesses and poorer QoL in the caregiver population (Thomas, Saunders, Roland & Paddison, 2015). Further findings indicated that hours spent providing care, lower QoL, and lower self-compassion were predictive of higher rates of depression.

Time spent caregiving is shown to be associated with depression in vast bodies of work (Covinsky et al., 2003), and recent work has demonstrated that this relationship is mediated by This association was mediated by losses of time for other activities, income, and sense of community (Hilbrecht et al., 2015), each of which were likely in the present study given the high rates of unemployment and daily time spent providing care. Whilst participant reports of time spent caregiving likely reflect the high demand of caring for someone with a long-term or neurological condition, it is possible that those exhibiting more severe depression perceived themselves to be spending more time providing care. Further work is therefore required to establish the direction of this relationship.

In addition to time spent caregiving, both QoL and self-compassion were also predictors of depression, explaining almost half of the variance. This is perhaps unsurprising, given the large effect observed for the relationship between compassion and mental health (MacBeth & Gumley, 2012). Further, self-compassion is shown to be a better predictor of depression symptom severity than mindfulness (Van Dam, Sheppard, Forsyth, & Earleywine, 2010), and yet interventions focused primarily on improving self-compassion remain scarce. This

215 evidence reinforces that self-compassion is a robust and important factor in psychological

216 wellbeing and QoL of partner caregivers. Indeed, self-compassion promotes positive health-

217 behaviours such as seeking medical help when needed (Terry & Leary, 2011) and engaging in

218 exercise (Magnus, Kowalski & McHugh, 2010), both of which are likely to improve both

219 depression and QoL. Individuals who have the ability to extend compassionate care to

220 themselves are able to recover and bounce back from stressors at a faster rate compared to

221 people with lower self-compassion (Figley, 2002; Leary et al., 2007). This highlights the

222 importance of developing self-compassion interventions for this high-risk group so as to

223 support them in increasing resilience to the demands of caregiving.

224

225 *Clinical Implications*

226 Developing a culture of self-compassion in partner caregivers of individuals with chronic

227 illnesses after diagnosis could potentially minimize their risk of suffering from mental health

228 related disorders and improve their QoL. Attempts have already been made to study

229 interventions with the aim to improve self-compassion, such as through the use of mindfulness-

230 based interventions, which have demonstrated reductions in stress and anxiety, and increases

231 in self-compassion (Shapiro, Brown & Biegel, 2007). Further, investment in support groups

232 and respite services for informal carers could further enhance self-compassion. Indeed, such

233 groups cultivate a sense of common humanity, which is central to self-compassion (Neff,

234 2011), and promote an environment where carers can receive support and companionship from

235 people with whom they share experiences.

236

237 *Limitations and Future Research*

238 Whilst the study provides unique insight into the potential role of self-compassion in the QoL

239 and psychological wellbeing of caregivers of people with long-term conditions, there are some

240   limitations to consider. The current study presents results from a small cross-section of mostly

241   female partner caregivers which limits the extent to which conclusions can be generalised and

242   causality inferred. The largely female sample likely represents the under-representation of male

243   carers in research and/or caregiving. There is urgent need to explore mental well-being and

244   QoL in the male carer population to explore the extent of variance in experiences and support

245   requirements.

246   Long-term follow-up research that also considers the length of the caregiver role should

247   be prioritised. Exploration of the impact of length of caregiving and the effects of fluctuations

248   in care needs on depression, QoL and self-compassion would be of value to identify the precise

249   timings when partner caregivers are likely to require more or less support. Moreover, detailed

250   information on the care-recipients pertaining to the type of long-term neurological condition

251   and the length of time they had been receiving care from their partner would provide more

252   insight on the relationship this has on quality of life, depression and self-compassion. Further,

253   qualitative investigations into the lived experiences of partner caregivers, and particularly

254   exploring how caregivers enact self-compassion and its role in their lives, will add in-depth

255   value to our understanding of this unique situation and its impacts.

256

257   *Conclusions*

258   The results of the present study serve to signpost researchers and clinicians towards potential

259   factors that may influence the health and wellbeing of partner caregivers. Indeed, developing

260   self-compassion in partner caregivers may help to improve outcomes for both the caregiver

261   and the care recipient, by potentially mitigating the impact of the caregiving role.

262

263   **Conflict of interest**

264   The authors declare no conflicts of interest.

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344

345   Table 1. Sociodemographic characteristics of caregivers.

		M	SD
	Age	58.24	25.5
	Hours (a day) spent at work	4	4.77
	Hours (a day) spent caring	8.90	6.40
		N	%
Gender	Male	14	25.5
	Female	41	74.5
Marital Status	Married	41	74.5
	In a relationship	9	16.4
	In a civil partnership	2	3.6
	Other	3	5.5
	Length of marriage/relationship (years)	25.62	13.55
Employment Status	Employed F/T	11	20
	Employed P/T	15	27.3
	Unemployed, looking for work	1	29.1
	Unemployed, NOT looking for work	10	1.8
	Retired	16	18.2
	Disabled, not able to work	2	3.6
Ethnicity	Asian/British Asian	4	7.3
	Black/African/Caribbean/Black British	3	5.5
	White British/Caucasian	43	78.2
	Mixed/Multiple ethnic groups	3	5.5

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348   Table 2. Frequency of chronic illnesses in care-recipients.

		N	%
Chronic/Neurological illness	Spinal Cord Injury	11	20
	Alzheimer's & Dementia	11	20
	Cancer	6	10.9
	Multiple Sclerosis	8	14.5
	Other	18	32.7

349

350

351 Table 3. Distribution of PHQ-9 scores according to Depression Diagnosis Status (N = 55)

Level of Depression Severity, PHQ-9 Score	N (%)
Minimal, 0-4	21 (39.18)
Mild, 5-9	16 (29.09)
Moderate, 10-14	8 (14.55)
Moderately Severe, 15-19	7 (12.73)
Severe, 20-27	3 (5.45)

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355   Table 4. QoL Domain scores of caregivers and non-caregivers from UK population.

QoL Domains	Population Norms (Hawthorne, Herrman, & Murphy; $N = 866$)		Caregivers (current study, N = 55)		p-value	95% CI (lower, upper)
	_M_	_SD_	_M_	_SD_		
Physical	73.5	18.1	51.9	10.1	< .001	16.76, 26.44
Psychological	70.6	14.0	53.5	9.1	< .001	13.34, 20.86
Social	71.5	18.2	56.4	17.6	< .001	10.14, 20.06
Environment	75.1	13.0	64.9	15.8	< .001	6.60, 13.80

356   n.b. percentages rounded to 1 decimal place.

357