

Experience of Loneliness associated with being an informal caregiver: a qualitative investigation

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The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest

Author contribution statement

JB, MB, JV, SL and MW had substantial contribution to the conception of this work. KV and JB designed the study. KV collected and analysed the data and all authors had substantial contribution to the interpretation of the data. KV drafted a previous version of this article and all authors critically revised it for important intellectual input and finally approved of the version to be published. All authors agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

Keywords

Loneliness, Social Isolation, Informal caregivers, qualitative interviews, experiences, United Kingdom

Abstract

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Although providing care to a family member or friend may provide psychological benefits, informal (i.e. unpaid) caregivers also encounter difficulties which may negatively affect their quality of life as well as their mental and physical health. Loneliness is one important challenge that caregivers face, with this psychological state being associated with morbidity and premature mortality. Although previous research has identified loneliness as an issue associated with being an informal caregiver, there is a paucity of evidence that attempts to understand this phenomenon in depth. This study aimed to examine informal caregivers' reflections on, and accounts of, experiences of loneliness linked to their caregiving situation. A cross-sectional, qualitative study was designed. Sixteen semi-structured interviews were conducted with 8 spousal caregivers, 4 daughters caring for a parent, 3 mothers caring for a child (or children) and 1 woman looking after her partner. The cared-for persons were suffering from a range of mental and physical health conditions (e.g. dementia, frailty due to old age, multiple sclerosis, depression, autism). Data were analyzed using an inductive thematic analysis. Experiences of loneliness were described by reference to a context of shrunken personal space and diminished social interaction caused by the restrictions imposed by the caregiving role. Loneliness was also articulated against a background of relational deprivations and losses as well as sentiments of powerlessness, helplessness and a sense of sole responsibility. Social encounters were also seen to generate loneliness when they were characterized by some form of distancing. Though not all sources or circumstances of loneliness in caregivers are amenable to change, more opportunities for respite care services, as well as a heightened sensibility and social appreciation of caregivers' valued contributions could help caregivers manage some forms of loneliness.

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This study was carried out in accordance with the recommendations of the British Psychological Society. The study protocol received ethical approval from the Department of Psychology (Ethical approval reference number: 15-149) at the University of Bath and the Ministry of Defence Research Ethics Committee (Application number: 620/ModREC/14). All participants gave written informed consent in accordance with the Declaration of Helsinki.

In review

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14 **United Kingdom.**

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26 **Abstract**

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29 well as their mental and physical health. Loneliness is one important challenge that caregivers face,
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31 previous research has identified loneliness as an issue associated with being an informal caregiver,
32 there is a paucity of evidence that attempts to understand this phenomenon in depth. This study
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44 or circumstances of loneliness in caregivers are amenable to change, more opportunities for respite
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46 contributions could help caregivers manage some forms of loneliness.

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61 **1 Introduction**

62 Loneliness and social isolation are increasingly recognized as important societal challenges.
63 Approximately 15% of adults in the UK aged 16-79 years old report high levels of loneliness in their
64 daily life with double this percentage in people aged over 80 (Thomas, 2015). Loneliness is defined
65 as “the unpleasant experience that occurs when a person’s network of social relations is deficient in
66 some important way, either quantitatively or qualitatively” (Perlman and Peplau, 1981, 31). Despite
67 being associated with social isolation – a situation which refers to a quantitatively diminished social
68 network – loneliness is considered to be a distinct concept which necessitates a *subjective* and
69 *negative* evaluation of the existing status of one’s social network (Yang and Victor, 2011).
70 Depending on the nature of the social deficit that is involved, two types of loneliness have been
71 proposed (Weiss, 1973): *Emotional loneliness* occurs when one lacks intimate and close relationships
72 and *social loneliness* results from inadequate integration with social networks (e.g. derived from
73 employment, kin, friendships, or neighborhood), or rejection by the broader community (e.g. residing
74 in an unaccepting community). Loneliness can negatively influence higher-order cognitive processes
75 (e.g. attention, memory, emotional regulation, logical reasoning) (Cacioppo and Hawkley, 2009) and
76 manifest affectively in desperation, depression, boredom and self-deprecation (Rubenstein and
77 Shaver, 1982). Behaviorally, lonely people tend to encounter others in a more self-absorbed and less
78 socially effective manner than non-lonely individuals (Heinrich and Gullone, 2006).

79 Given the crucial role of social relationships and social support networks in health and well-being
80 (Cohen, 2004; Holt-Lunstad et al., 2010), a substantial body of research has examined the links
81 between loneliness and social isolation and physical and mental health outcomes. Research suggests
82 that loneliness and social isolation are associated with increased likelihood of mortality (Holt-
83 Lunstad et al., 2015; Holwerda et al., 2016; Pantell et al., 2013), increased risk of developing
84 coronary heart disease, stroke (Valtorta et al., 2016) high blood pressure (Hawkley et al., 2010) and
85 engagement with unhealthy behaviors (e.g. smoking, alcohol consumption) (Lauder et al., 2006;
86 Nieminen et al., 2013). Loneliness is also related to poor mental health outcomes (for a review see
87 Heinrich and Gullone, 2006), such as depression (Cacioppo et al., 2010; Teo et al., 2013), deliberate
88 self-harm (Rönkä et al., 2013), increased risk of dementia (Holwerda et al., 2014) and Alzheimer’s
89 disease (Wilson et al., 2007). It is also associated with increased frequency of older adults’ visits to
90 their doctor (Ellaway et al., 1999; Gerst-Emerson and Jayawardhana, 2015), thus impacting on
91 healthcare costs.

92 Despite agreement about the subjective nature of the phenomenon of loneliness, most research in the
93 area has historically tended to be quantitative, limiting understanding of the lived experience of
94 loneliness. In response to this, more recent research endeavors employing qualitative methods have
95 been directed to an examination of the ways people experience and make sense of loneliness
96 (Dahlberg, 2007). Given the emphasis on loneliness in *older age*, most qualitative (or mixed-method)
97 research has been conducted with older people (e.g. Graneheim and Lundman, 2010; Hauge and
98 Kirkevold, 2012; Stanley et al., 2010; Tiilikainen and Seppänen, 2016). However, loneliness has
99 been explored in other populations, such as people with mental health problems (e.g. Lindgren et al.,
100 2014), those with intellectual disabilities (e.g. McVilly et al., 2006), school-aged children (e.g.
101 Berguno et al., 2004), adolescents (e.g. Ruiz-Casares, 2012), and students (e.g. Sawir et al., 2008).
102 This literature reveals the complex, diverse, and multifaceted nature of the experience of loneliness
103 that is contingent on contextual and person-related factors.

104 Important life transitions that induce changes in one’s existing or desired social relations and
105 interactions can precipitate the onset of loneliness (Peplau and Perlman, 1982; Perlman and Peplau,

106 1981). Taking on a caregiving role often constitutes such a transition; a major life event that is likely
107 to disrupt one's status of social relations. An informal caregiver is defined as the person who (in
108 contrast to professional caregivers) provides unpaid care to a family member, partner, friend or
109 neighbor because of long-term physical or mental ill health, disability, or problems related to old age.
110 The caregiver can either co-habit with the cared-for person or not and care provision can range from
111 a few hours per week to round-the-clock (Carers UK, 2015). Informal caregivers constitute a sizeable
112 minority of the general population. According to 2011 census data, 5.8 million people in England and
113 Wales provided informal care to a family member, friend, or neighbor, representing just over 1 in 10
114 of the population (Office for National Statistics, 2013). Indeed everyone is likely to become a
115 caregiver at some point in their lives as care demand is estimated to grow in the future (Office for
116 National Statistics, 2013). For example, estimates suggest that 9 million caregivers will be needed in
117 the UK by 2037 (Carers UK, 2015). The majority of caregivers in Britain are people of working age
118 with the peak age of caregiving being between 50 and 64 years old. 58% of caregivers are female,
119 42% are male and the majority look after their parents or parents-in-law (40%) or their spouse or
120 partner (26%) (Carers UK, 2015).

121 Despite the identification of some psychological benefits that arise from providing care to a family
122 member or friend, such as a sense of greater closeness toward the cared-for individual or enhanced
123 sense of purpose and meaning in life (Cohen et al., 2002; Kramer, 1997; Mackenzie and Greenwood,
124 2012), the strain of caregiving role places this population at risk of poor psychological and physical
125 health (Pinquart and Sörensen, 2003; Vitaliano et al., 2003). Research indicates that caregivers have
126 higher levels of stress and depression and lower levels of subjective well-being than non-caregivers
127 (Pinquart and Sörensen, 2003; Verbakel, 2014) and encounter a greater risk of developing physical
128 health problems (Vitaliano et al., 2003), particularly those caregivers who are psychologically
129 distressed and/or face behavioral difficulties of the cared-for person (Pinquart and Sörensen, 2007).
130 The caregiving role can also restrict caregivers' participation in social activities (Clark and Bond,
131 2000) thus limiting the psychological benefits that accessing social support offers (Cannuscio et al.,
132 2004) as well as the opportunity for a satisfying social life.

133 Though prevalence studies are lacking, it has been estimated that 8 in 10 caregivers in the UK have
134 felt lonely or socially isolated as a result of their caregiving situation (Carers UK, 2015). Supporting
135 these estimates, qualitative research with men caring for a spouse or a parent has identified feelings
136 of loneliness to be one of the significant elements of the caregiving experience (Parsons, 1997;
137 Siriopoulos et al., 1999) and cross-sectional research shows that caregivers report higher levels of
138 loneliness than non-caregivers (Beeson, 2003). Loneliness in the caregiving population appears to be
139 qualitatively different from the one reported by the general population with caregivers scoring higher
140 levels on the aspect of self-alienation (Rokach et al., 2007). Characteristics such as lower educational
141 level, low self-efficacy, poorer physical health and being a female are predictive of loneliness in
142 caregivers (McRae et al., 2009; Soylu et al., 2016). Finally, loneliness in caregivers is associated with
143 psychological distress (Chukwuorji et al., 2016) and significantly predicts depression (Beeson et al.,
144 2000; Beeson, 2003) and low quality of life (Ekwall et al., 2005).

145 The present study used a qualitative methodology to examine how informal caregivers, encountering
146 a diversity of caregiving situations, experience and make sense of loneliness linked to their
147 caregiving situation. Given the significant links, as noted above, between loneliness, health and well-
148 being as well as the health-related challenges that caregivers face more broadly, by virtue of the
149 stressors of their caregiving context, it is timely to pay closer attention to caregivers' experiences of
150 loneliness.

151 2 Methods

152 2.1 Study context and design

153 The study reported here is part of a larger mixed-method research project that examines experiences
 154 of loneliness – defined as the distressing experience deriving from a discrepancy between one’s
 155 desired and actual levels of social relations (Perlman and Peplau, 1981) – in people whose social
 156 relations are likely to alter and be disrupted on account of work situations (i.e. lone and remote
 157 working) and major life changes and transitions (i.e. assuming a caregiving role; moving away from
 158 home to study). This research project also seeks to investigate how digital technologies can facilitate
 159 social exchanges that are characterized by empathy and trust that might, in turn, alleviate experiences
 160 of loneliness and foster meaningful and satisfying social connections. The findings presented in this
 161 paper come from the cross-sectional qualitative exploratory phase of the project during which 45
 162 semi-structured interviews were conducted with informal caregivers (n = 16), students (n = 154), and
 163 remote and lone workers (n = 14). This study was carried out in accordance with the
 164 recommendations of the British Psychological Society. The study protocol received ethical approval
 165 from the Department of Psychology (Ethical approval reference number: 15-149) at the University of
 166 Bath and the Ministry of Defence Research Ethics Committee (Application number:
 167 620/MoDREC/14). All participants gave written informed consent in accordance with the
 168 Declaration of Helsinki.

169 2.2 Study population, sampling and recruitment

170 The study population of the research reported in this article consisted of informal caregivers who
 171 self-identified as experiencing some form of loneliness and/or social isolation associated with their
 172 responsibilities of providing care and who reported that they had significantly limited their activities
 173 as a result of their caregiving role. A non-probability purposive sampling approach was thus adopted
 174 that allowed us to recruit caregivers who were likely to provide rich and in-depth accounts of
 175 experiences of loneliness. Participants for this study were recruited with the assistance of a voluntary
 176 organization in the South West England. Around 3,500 caregivers are registered with this
 177 organization, of which 500 are young caregivers. Of the adult caregivers, 69% are female and 31%
 178 are male. The average age of the adult caregivers registered with the organization is 57 years old.

179 Two-hundred research invitation letters were sent to caregivers registered with the voluntary
 180 organization describing briefly the study. Seventy-five caregivers expressed an interest in finding out
 181 more about the research by returning their contact details to the researchers, using a pre-paid
 182 envelope. Prospective participants were then provided with: (a) a *Participant Information Sheet*
 183 explaining in greater detail the aims of the study, the research process, and their rights as research
 184 participants; (b) an *Informed Consent Form* to be signed prior to the interview; and (c) a *short*
 185 *Screening Questionnaire* (please refer to Supplementary Material: Screening questionnaire). The
 186 screening questionnaire was used to collect basic demographic data (i.e. gender, age, educational
 187 level, nationality and marital status), information about the caregiving situation (i.e. caregiver’s
 188 relationship to the cared-for person; duration of caregiving situation; number of hours providing care
 189 on a ‘typical’ day; access to respite care; and extent to which the caregiver had limited or stopped
 190 activities as a result of the caregiving role) and information about the use of communication
 191 technologies, including any potential use of digital technologies. Twenty-eight caregivers returned
 192 their screening questionnaire. From those, 16 caregivers who replied back within the timeframe of
 193 the data collection period and reported in their screening questionnaire significant activity restriction
 194 due to the caregiving situation (‘somewhat’ or ‘very much’) were invited to the interview to meet
 195 sampling requirements.

196 2.3 Participants

197 In total 16 caregivers (11 women; *Mean* age = 63 years old, *min* = 24, *max* = 91; 12 participants \geq 59
 198 years old) were interviewed. Eight participants were spousal caregivers; one woman was caring for
 199 her partner; four caregivers were looking after a parent; and three caregivers were mothers caring for
 200 their child or children with significant health problems. Seven participants were caring for somebody
 201 with dementia, six people were looking after someone with primarily a physical illness (one case,
 202 physical illness and depression), and the three mothers looked after children with a psychological or a
 203 developmental disorder. All caregivers were living with the cared-for person, except for one mother
 204 who lived separately from her adult daughter at the time of the interview. Four of the participants
 205 were assisted by professional caregivers at home and three regularly accessed respite services.
 206 Fourteen caregivers were British (two did not report their nationality); six caregivers had received
 207 higher education; seven had received education to less than university degree level; and three
 208 participants reported no qualifications. Table 1 presents the participants' demographic characteristics
 209 and the health status of the cared-for person. In the analysis section below, the interview
 210 identification code, the participant's gender, age and relationship to the cared-for person are provided
 211 after each quotation to contextualize the accounts.

212 [INSERT TABLE 1 HERE]

213 2.4 Data collection

214 Date were collected in October and November 2015. In accordance with caregivers' wishes, 11
 215 interviews were conducted at participants' home, 3 at the University of Bath and 1 at the premises of
 216 the voluntary organization through which participants were recruited. A semi-structured interview
 217 protocol was developed to guide the conversations (please refer to Supplementary Material:
 218 Interview objectives and protocol). The interview was divided into two main parts. In the first
 219 section, participants were invited to discuss their caregiving situation (e.g. how they took up their
 220 caring responsibilities and what these included; duration of the caring situation; the main challenges
 221 they have faced; the impact of the caring situation on caregivers' life; available support from family,
 222 friends and outside organizations and agencies). The second part of the interview explored
 223 experiences of loneliness and social isolation as well as any management strategies the caregivers
 224 had developed to cope with these experiences. To close the interview, participants were invited to
 225 add any final thoughts or observations they wished to make around experiences of loneliness in
 226 caregivers more broadly. The interviews lasted on average one hour (shortest = 25 minutes; longest =
 227 90 minutes), were audio-recorded and were then transcribed verbatim. At the end, participants were
 228 provided with a debrief sheet which included a list of support contacts. Participants were also offered
 229 a High Street voucher as a token of appreciation for contributing to the research. The first author, a
 230 psychologist by education with extensive experience in qualitative research, conducted the
 231 interviews.

232 2.5 Analytic approach

233 A thematic analysis was adopted to analyze the data using the six-phase process suggested by Braun
 234 and Clarke (2006, 2012). Thematic analysis is a suitable analytic approach for identifying "patterns
 235 of meanings across a data set" in a systematic manner (Braun and Clarke, 2012, 57). Moreover, this
 236 analysis was informed by a critical realist epistemological standpoint (Bhaskar, 1989). Situated
 237 between a naïve realist and a purely relativist position, critical realism assumes that language is
 238 constitutive of social realities and meaning. Nevertheless, extra-discursive elements – in particular
 239 material conditions – also impact upon meaning and subjectivity by delimiting which discursive

240 constructions are more or less dominant, and thus more or less available (Sims-Schouten et al.,
 241 2007). Taking a critical realist standpoint allowed us to examine caregivers' discursive constructions
 242 of experiences of loneliness while also being attentive to the significance and influence of the
 243 material contexts within which they operated (e.g. the cared-for person's health status). Though pure
 244 induction is unattainable, as the researcher can never completely escape their own pre-conceptions,
 245 this analysis largely employed a bottom-up, data-driven approach, which sought to empirically
 246 ground how participants themselves made sense of their experiences of loneliness.

247 3 Results

248 Four main themes were identified from the analysis: (a) Loneliness was located within a context of
 249 *shrunk personal space* and *diminished social interaction* resulting from the restrictions posed by
 250 the caregiving role; loneliness was articulated against (b) a background of *relational deprivations* and
 251 *losses*, as well as (c) social encounters characterized by some form of *distancing* and *separateness*;
 252 (d) finally, sentiments of *powerlessness*, *helplessness* and a sense of *sole responsibility* were
 253 considered to induce feelings of loneliness.

254 3.1 Theme 1: Shrunk personal space and diminished social interaction

255 Experiences of loneliness in informal caregivers were often seen to be linked to the restrictions that
 256 the caregiving situation imposed. Participants commonly articulated how their everyday life was
 257 characterized by limited freedom to define the management of their time and choice of space, by a
 258 lack of spontaneity, and with little opportunity to be free from concern. The needs and well-being of
 259 the cared-for person were a constant pre-occupation and priority, whilst time away from the care
 260 receiver required considerable planning on the part of the caregiver.

261
 262 *I can't do so much as I used to do. I can't leave him in the house, I can't go off and leave him,*
 263 *he's always got to be with me. My life has narrowed down a bit.* (P05: Female, 81, cares for
 264 husband)

265
 266 The sense of restriction was very intense in some instances, as illustrated through the use of
 267 imprisonment as an analogy.

268
 269 *That was lovely to get out and just be out, you know? We were doing something for ourselves,*
 270 *you know? It was like we'd been let out a cage or something?!* (P07: Female, 60, cares for
 271 mother).

272
 273 Some participants described that they missed the freedom and spontaneity to be able to meet friends
 274 outside the home for as long as they wanted to and whenever this opportunity arose. And although
 275 participants expressed the view that this restriction could to some extent be counterbalanced by
 276 inviting friends to their house, they simultaneously acknowledged that this sort of social interaction
 277 has limitations as it depends on other people's availability and willingness to visit them as well as on
 278 the cared-for person's sense of comfort and receptiveness to regularly have visitors at home.

279
 280 *I miss going out with my friends, they all go all over the place still and they're all widows*
 281 *mainly. They do what they want and go out and enjoy themselves, which is right, but I can't*
 282 *do that because I can't leave him and I haven't got anyone to come and look after him. So*
 283 *that's difficult, I find that really difficult that I can't go out just when I want to.* (P01: Female,
 284 82, cares for husband)

285

286 In discussing their views as to whether loneliness might be a common challenge among the
 287 caregiving population, the participants considered that feelings of loneliness are prevalent in
 288 caregivers due to the disconnection and social isolation that the caregiving situation induces. The
 289 simile of new mothers who are entirely committed and devoted to the needs of the new-born baby
 290 was used by one participant to explain why caregivers might be particularly susceptible to loneliness.

291

292 *Because you [‘re] cut off, your life is so involved with that person, you’re cut off from so much*
 293 *because you just are so involved. It’s very much like a mum who’s caring on her own or even if*
 294 *her partner’s away at work and she’s got a new baby, she’s so involved in what she’s got to do,*
 295 *she may not have the friends or the family or the opportunity to link in so in the same way, it’s*
 296 *like that. (P08: Female, 69, cares for father).*

297

298 Loneliness was exacerbated by the requirement of constant attentiveness to the cared-for person,
 299 which significantly shrank the caregiver’s real and psychological space. The boundaries between the
 300 self and the other were forced to be drawn in ways that limited the fulfilment of the caregiver’s social
 301 needs and desires. This created tension between the requirements of the caregiving role and the
 302 caregiver as a person.

303

304 *You can forget about yourself. I battle with these ‘me time’ ideas because I think as a carer or*
 305 *as a mother, your role is to care and to look after, but the self does get overlooked and if you*
 306 *can’t get out, if you can’t meet other people and you’re just one to one with the person you’re*
 307 *caring for, it might not be all day but for significant parts of the day, then even though you’ve*
 308 *got the company of that person, it can be very lonely. (P15: Female, 48, cares for two children*
 309 *with disabilities).*

310

311 Despite the significance of the need for relatedness to others, the aforementioned extract illustrates
 312 that the fulfilment of sociability cannot readily be prioritized over caregiving, perhaps in part due to
 313 the moral character of caregiving and the prescriptions of the role (*‘I think as a carer or as a mother*
 314 *your role is to care and to look after’*). This finding is in line with research that demonstrates the
 315 centrality of morality in perceiving and evaluating ourselves and others (Brambilla and Leach, 2014;
 316 Ellemers et al., 2014).

317

318 Alongside the limited opportunities for satisfaction of social needs, participants also linked feelings
 319 of loneliness and isolation to their restricted ability to look after themselves and pursue leisure
 320 activities from which one can derive pleasure.

321

322 *When you’re looking after someone all the time, you’re thinking about them a lot more than*
 323 *you’re thinking about your own health, and so that can be really isolating because you stop*
 324 *putting yourself first and you stop looking at what your hobbies are and what makes you happy*
 325 *and things like that. (P04: Female, 24, cares for partner)*

326

327 **3.2 Theme 2: Relational losses and deprivations**

328 Loneliness was further linked to the losses and deprivations the caregiver incurred with regard to
 329 important close relationships. These deprivations mainly concerned the caregiver’s relationship with
 330 the cared-for person, especially in cases where this person was a spouse with dementia.

331

332 ...the loneliness is there even when I'm with [wife's name] because in reality, I am on my own
 333 because she's not relating, there's no conversation other than the weather or the trees,
 334 perhaps a bit about the garden, something like that. (P12: Male, 71, cares for wife)

335
 336 The worse [partner's name] feels, the more lonely I feel. So he has periods where he doesn't
 337 seem like he's communicating with the outside world, so you'll ask him things, he's just very
 338 blank, sort of blank, wide eyed stare, not really there. (P04: Female, 24, cares for partner)

339
 340 But even when the cared-for person's health status did not severely affect the couple's ability to
 341 communicate and relate with each other, experiences of loneliness were thought to emerge from the
 342 loss of activities and routines that the couple used to enjoy in the past, prior to the onset of illness.

343
 344 I'm lucky, I haven't lost [wife's name], I can still speak to [wife's name] and that but we can't
 345 do as much as we used to, we can't go out walking the dog together, can't go out riding bikes
 346 together. Can't walk around too far. So yes, that's the reason why, because you've got that
 347 person. If you're caring for a stranger or somebody who has had their condition for two or
 348 three years before you started caring for them, not sounding hard but you don't know that
 349 person for the person they used to be. So with a loved one, you lose that person, like I said
 350 with [wife's name] and me it's walking, doing bikes and that. With my dad, when mum was
 351 ill, in a way he lost his wife because she couldn't talk and recognize him and nothing like
 352 that. (P03: Male, 41, cares for wife)

353
 354 Not only was the relationship, or the shared life, with the cared-for person disrupted severely, but
 355 other important relationships within the broader family context were also negatively affected by the
 356 caregiving situation. The re-arrangement of these relationships on both practical and emotional levels
 357 necessitated by the caregiving situation was sometimes identified as a source of loneliness.

358
 359 We rarely go out as a couple, actually that's quite an impact, we rarely go out as a couple
 360 these days because it has to be very carefully organized.

361
 362 It can be very lonely and within, my husband and I, I can feel quite lonely there because [name
 363 of child with autism] does push a wedge between us and so that's, I feel quite lonely in some of
 364 the approaches I make. (P15: Female, 48, cares for two children with disabilities)

365
 366 A few participants who were caring for an older parent and had themselves become grandparents
 367 referred to the deprivations they experienced with regards to the relationship they desired to build and
 368 enjoy with their grandchildren. The time that was not presently possible to be invested in these
 369 relationships, whilst the grandchildren were still little, due to the caregiving situation was considered
 370 invaluable, and to some extent irreplaceable, for the building of memories in the future.

371
 372 I'm going to use quite a strong word, I resent not being able to say, "We'll take [grandchild's
 373 name] away this weekend", it's everything has got to be planned and that is a strong word,
 374 but I do. [Grandchild's name]'s growing up fast, as children do, he's not going to want to go
 375 out with his grandparents for weekends, although having said that his sister did and she's 22
 376 in January and it's lovely, they do want to be with us but we want to do special things with
 377 him, which we did with the girls when they were younger and those memories are important, I
 378 think. So that's sadly been curtailed and we need to do something about that, I know, but
 379 yeah, life has changed. (P08: Female, 69, cares for father)

380 **3.3 Theme 3: Social interactions and distancing**

381 Loneliness was not only related to a lack or loss of social relationships, but also to a lack of
 382 satisfaction with existing moments of social interaction. Feelings of loneliness were located within
 383 social interactions characterized by a lack of understanding, ignorance of the challenges the caregiver
 384 faces, and a lack of recognition and acknowledgement of caregivers' contribution, through to a
 385 judgmental or even exclusionary stance. Some participants narrated moments of loneliness when they
 386 had felt that other people could not genuinely understand them and their situation and did not really
 387 know what the caregiver was going through. The loneliness associated with the subjective sense that
 388 other people 'don't really understand' was described by one participant as a form of 'inward
 389 loneliness' that persisted despite the building of a network of friends which combatted the 'outward
 390 loneliness'.

391
 392 *R: ...and then I made friends, eventually when we got him into [the name of] School, then that*
 393 *gave me another network but there's the outward loneliness but there's also the inward*
 394 *loneliness as well and I still actually feel quite inwardly lonely.*

395 *Int: How does this feel?*

396 *R: It just feels very empty and numb, I feel quite numb sometimes, just how to... I don't want*
 397 *to be self-pitying but it can be very lonely, that people don't really understand. (P15: Female,*
 398 *48, cares for two children with disabilities)*

400 Social encounters whereby the participants felt that other people unfairly judged them triggered the
 401 sense of lack of understanding which, in turn, was linked to feelings of loneliness.

402
 403 *R: And I feel like people don't understand what's happening with me a lot of the time.*

404 *Int: Why are you saying that?*

405 *R: Because they're not living it and they're not asking about it either. They'll meet [partner's*
 406 *name]. They'll meet up with him and be like oh, he's clearly really ill at the moment, but*
 407 *sometimes I can be quite moody because things are difficult, and I'm tired and I'm working*
 408 *hard. So then people can just think like [partner's name]'s ill and [participant's name]'s just*
 409 *being horrible today, so I'm not going to bother talking to her for a bit and things like that.*
 410 *So yeah it's difficult. (P04: Female, 24, cares for partner)*

411
 412 The inability of others to understand and empathize with caregivers was considered more likely when
 413 the illness of the cared-for person was not readily observable, or of a psychological nature, in which
 414 case it was thought to be less well understood by the majority of people. Indeed, a mother caring for
 415 her son with Attention Deficit Hyperactivity Disorder and high functioning autism narrated her
 416 annoyance and wounded feelings when other people questioned the legitimacy of her son's diagnosis
 417 and denied the 'real existence' of the disorder. This, in turn, challenged her own status as a
 418 'caregiver', an identification that provided her with the legitimacy to seek extra help and support.

419
 420 Feeling completely understood by others was not nevertheless seen as entirely attainable, unless other
 421 people had experienced a similar caregiving situation. For this reason interacting with 'similar others'
 422 in terms of the caregiving situation and the health status of the cared-for person created a sense of
 423 familiarity and comfort among people who could genuinely understand each other.

424
 425 *That's the other nice thing, when you get talking to people with children that are like yours,*
 426 *you realize it's very different, but very similar if that makes sense but again, it's a comfort to*
 427 *know my child's not the only one who does that, "your child does that as well", things like the*

428 *diet and the running off. I remember having a conversation with someone and saying, “[son’s*
 429 *name]’s a runner” and she started laughing, she said “I’m sorry, I shouldn’t laugh but*
 430 *sometimes you’ll say to someone ‘my child is a runner’ and they look at you what you’re on*
 431 *about, but I know exactly what you mean”, and that was quite nice because she knows what*
 432 *the runner is! (P16: Female, 46, cares for son)*

433
 434 Alongside a lack of understanding and empathy, or, even a sense of judgment and subtle
 435 condemnation, a lack of recognition and acknowledgement of caregivers’ valuable and often ‘hidden’
 436 contribution to the care recipient’s well-being was considered to be a further source of loneliness.
 437 One participant, who claimed that she did not feel lonely as a person because of the nature of the
 438 relationship with her husband, admitted that she was experiencing a form of loneliness that was
 439 linked to a lack of recognition of her role as a caregiver. This lack of acknowledgement concerned
 440 the world of ‘non-caregivers’ but was also narrated within the context of exchanges with healthcare
 441 professionals.

442
 443 *I know people are busy, I am very aware, incredibly aware how busy these services are in the*
 444 *care services and NHS [National Health Service] but the thought, if only at that front door,*
 445 *ringing the bell, thinking, “that’s my primary client, the elderly gentleman/lady needs support*
 446 *but what about the people that are helping them? I need to link with them”, just a couple of*
 447 *words, some acknowledgement, it makes a big difference. (P08: Female, 69, cares for father)*

448
 449 The positioning and ‘visibility’ of the informal caregiver within the healthcare services context were
 450 even more problematic when the cared-for person was an adult child suffering from mental illness.
 451 Overstretched mental health services, the confidentiality protocols between the patient and healthcare
 452 professionals, and the uncertainty around the prognosis of the illness were seen to hamper a fruitful
 453 involvement of the caregiver, which would also be sensitive and attentive to the caregiver’s
 454 informational and emotional needs.

455
 456 *You are really alone with those feelings because I think as a carer, what you really need to be*
 457 *honest is reassurance that you’re doing the right thing and you don’t get it. I’ve never really*
 458 *had it from the recovery service actually, thinking about it now, I never really have had PIP*
 459 *or anybody say, “You’re doing a really good job”. (P14: Female, 59, cares for daughter).*

460
 461 Finally, an extreme case of social encounter, characterized by distancing, was offered when a mother
 462 narrated an instance of social exclusion linked to her child’s health status. This exclusionary social
 463 interaction, which triggered a realization that the family was ‘*very visibly different to the outside*
 464 *world, to the other children’ (P15: Female, 48, cares for two children), was then associated with*
 465 *intense feelings of isolation.*

466

467 **3.4 Theme 4: Powerlessness, helplessness and sole responsibility**

468 Experiences of loneliness were linked to feelings of helplessness and impotence when caregivers
 469 faced particular caregiving moments that were experienced as difficult and when help from others
 470 was not readily accessible as well as to a general sense of powerlessness to improve the cared-for
 471 person’s situation. Related to these, a heightened sense of sole responsibility for the cared-for
 472 person’s welfare was also offered as a context to situate feelings of loneliness.

473

474 Although most participants in this study were able to seek and receive satisfying support from family
 475 and friends, the inability to ‘solve’ the problems that the person they cared for faced still generated
 476 experiences of loneliness. Loneliness, in these instances, was located within a context of
 477 powerlessness whereby caregivers lacked control and efficacy.

478
 479 *I'm really lucky that I've got good friends and family and particularly my stepmother is*
 480 *incredibly supportive. But it's not loneliness in feeling you've got nobody to turn to, it's*
 481 *loneliness in that nobody can really help in a way. (P14: Female, 59, cares for daughter)*

482
 483 *I'm not lonely because of [husband's name] but there are other aspects of being lonely, lonely*
 484 *in terms of feeling isolated and lonely and not being able to find a solution, that sort of*
 485 *loneliness, does that make sense? (P08: Female, 69, cares for father)*

486
 487 Alongside a general sense of powerlessness, accounts of concrete caregiving moments that were
 488 experienced as particularly difficult were also offered to situate experiences of loneliness. The
 489 inaccessibility of help from others during these moments and the salience of the caregiver identity as
 490 it was being enacted, led to a profound sense of being alone and helpless in the caregiving role,
 491 which, in turn, was linked to feelings of loneliness.

492
 493 *For me, speaking from my own personal thing, I think it's that time when [wife's name] is not*
 494 *well and she's in bed and stays in bed. Sometimes she can have really bad things, stay in a*
 495 *bed for about a day to two days and in that time obviously I won't go out, I'll stay with her.*
 496 *I'll do things but I won't go out. So I think it's that time between me getting up and [wife's*
 497 *name] getting up I think is when I'm loneliest. So yes, I think it's when that time, because*
 498 *your friends aren't there for you then, they're not going to be there for you or they're not*
 499 *going to be there when you've got to get up in the middle of the night and do stuff...so it's*
 500 *those kind of times when you're on your own and it's those times when you can't speak to*
 501 *somebody or they can't come to you. (P03: Male, 41, cares for wife)*

502
 503 *It's almost an instantaneous thing, the loneliness of having to deal with an unexpected*
 504 *problem or a situation, which is usually related to a delusion of some sort and then it passes.*
 505 *Only in the way that perhaps if somebody else was there, you could quite quickly change the*
 506 *focus, you could say "[person's name] is there" or whatever, "[wife's name], why don't you*
 507 *tell so and so about what you did or tell her about the people on the bus?". But if you're there*
 508 *and trying to deal with that, it's the fact that it's unexpected, you're suddenly thinking on your*
 509 *feet how best to deal with this and you sometimes feel, "I could do with some help", that's*
 510 *basically really. (P12: Male, 71, cares for wife)*

511
 512 The cared-for person's dependence and reliance on the caregiver and the accompanied sense of sole
 513 and exclusive responsibility were occasionally seen to provoke loneliness and an intense realization
 514 of ultimately ‘being on your own’. For instance, a participant, who used to work as a nurse and as a
 515 result of this felt confident in looking after her mother, described a form of loneliness she felt when
 516 she noticed after her retirement that she could not share anymore the caregiving duties.

517
 518 *And I think that's what, when I first retired, I did have a sort of loneliness of you can't share*
 519 *the duties. You see I've always been so used to sharing, team work but suddenly you realize*
 520 *that this mum is the person you've got to look after yourself. No-one else is going to put the*
 521 *rubbish out, no-one else is going to change the bed and that can become quite, "Oh dear, why*
 522 *do I have to do everything?". (P09: Female, 69, cares for mother)*

523
 524 Feelings of loneliness were thus triggered by the lack of presence of others when the others were
 525 needed (i.e. moments of helplessness) and an accompanied sense of sole responsibility, but they were
 526 also experienced despite the presence of others and provision of their support (i.e. moments of
 527 powerlessness), suggesting the multiplicity of circumstances as constitutive of experiences of
 528 loneliness.
 529

530 4 Discussion

531 Designing effective support services and interventions to alleviate loneliness in the caregiving
 532 population requires detailed understanding of the phenomenon from the perspective of caregivers
 533 themselves. Recognizing a lack of qualitative evidence in this area, the present study sought to build
 534 an in-depth, empirically-grounded picture of experiences of loneliness in informal caregivers in a
 535 variety of caregiving situations. Consistent with findings from previous qualitative research in the
 536 phenomenon of loneliness (Dahlberg, 2007; Tilikainen and Seppanen, 2016; Stanley et al., 2010), the
 537 results of the present study suggest that this psychological state in the caregiving population is
 538 similarly complex and multifaceted. Feelings of loneliness were seen to derive from a series of
 539 challenges to relationships that threatened caregivers' fundamental need to belong (Baumeister and
 540 Leary, 1995). The moral character of the caregiving role that prescribed full attentiveness to the
 541 needs of the cared-for person subjected caregivers to the risk of social isolation and diminished social
 542 interactions which, at least in part, occasioned feelings of loneliness, as the need for sociability was
 543 thwarted (Brambilla and Leach, 2014). It simultaneously shrank caregivers' personal space and time
 544 reducing their ability for self-care and leisure. The relational losses and deprivations with regard to
 545 significant 'Others' – primarily the cared-for person – as well as social encounters that evoked a
 546 sense of being ignored, unappreciated, distanced, or even excluded (Williams, 2007) were also
 547 thought to generate loneliness, both emotional and social (Weiss, 1973). Lastly, a sense of lack of
 548 competence and control over the caregiving situation, of sole responsibility for the cared-for person's
 549 welfare, as well as circumstances where the inaccessibility of help was very salient, were linked to
 550 experiences of loneliness.

551 Moreover, the present results allude to the potential contribution of stigma to the generation of
 552 experiences of loneliness and isolation in the caregiving population. It was shown that especially in
 553 cases whereby the cared-for persons were suffering from psychological conditions, participants
 554 experienced covert (e.g. distancing, subtle condemnation) or even overt forms of exclusion. Courtesy
 555 stigma describes the stigma that is attached and burdens people who are closely affiliated (e.g. family
 556 members, friends) with individuals suffering from stigmatized conditions, such as mental health
 557 problems (Goffman, 1963). Courtesy stigma provokes discriminatory behaviors by others with
 558 people encountering labelling, stereotyping and separation. The internalization of courtesy stigma by
 559 family members, which has been described as affiliate stigma (Mak and Cheung, 2008), leads to
 560 negative self-evaluations and behaviors of social withdrawal and concealment of the condition (Ali et
 561 al., 2012). Both courtesy and affiliate stigma can therefore deprive caregivers of vital social support,
 562 both because social support is not provided or is denied by others and because it is not actively
 563 sought by caregivers who withdraw and confine themselves at home (Ntswane and Rhyn, 2007;
 564 Power, 2008).

565 Not all circumstances or sources of loneliness are open to change and intervention since many of the
 566 grounds of loneliness, such as the relational losses due to incurable illnesses or irreversible health
 567 situations, form an unavoidable reality. Yet, the present results suggest that there are aspects of the

568 caregiving experience which could be supported in ways that prevent or alleviate experiences of
569 loneliness. For instance, the heightened risk of social isolation that is conducive to loneliness could
570 be reduced by providing more opportunities for respite care services – or raising awareness of
571 existing possibilities – among the caregiver population that attend not only to the needs of the cared-
572 for person but also to the needs of the caregiver (Ashworth and Baker, 2000). More focused efforts to
573 sensitize the public to the valued contribution of caregivers and the challenges they face could fuel
574 greater social recognition and appreciation of this group and thus also have a role in reducing
575 courtesy and affiliate stigma. Finally, provision for the cared-for-person could be structured in ways
576 that include and value informal caregivers as well as specifically paying attention to caregivers’
577 needs (e.g. informational, emotional). The role of healthcare professionals in this is critical given that
578 the present findings indicate that loneliness in caregiving is sometimes derived from professionals’
579 lack of recognition and support.

580 **4.1 Strengths and limitations of the present study**

581 The limitations of the present study should be considered when interpreting the results. Our sampling
582 strategy sought to recruit a heterogeneous sample of caregivers with respect to their caregiving
583 situation, the illness of the cared-for person and the type of relationship with the cared-for person.
584 The heterogeneity of our sample allowed us to access a wide range of experiences and views and to
585 identify common features in experiences of loneliness linked to a diversity of caregiving situations.
586 Due to this sample heterogeneity however, although the reported themes were clearly identified, we
587 cannot exclude the possibility that additional themes would be detected should further interviews
588 have been conducted with particular sub-groups. The results offered here should therefore be
589 considered as a valid starting point upon which further empirical investigations could be built.
590 Moreover, to our knowledge this is the first study that has attended exclusively to experiences of
591 loneliness linked to a caregiving situation, a phenomenon that is increasingly acknowledged as a
592 considerable challenge of the informal caregiver population (Carers UK, 2015; Parsons, 1997;
593 Siriopoulos et al., 1999) where the focus of the emerging work is predominantly quantitative (e.g.
594 Beeson, 2003; Ekwall, et al., 2005; Soylu et al., 2016). Longitudinal investigations could further be
595 conducted to examine the potential fluctuations and differentiation of the experience of loneliness at
596 different phases of the caregiving journey (e.g. entering the caregiving situation, caring for an
597 individual at terminal stages of illness). A greater focus on the particularities of the experience of
598 loneliness arising from different caregiving situations would be also valuable in the effort to identify
599 risk factors associated with different subgroups of caregivers. Finally, future research would also
600 need to provide accurate estimates of the prevalence of loneliness in this population.

601 **4.2 Conclusion**

602 In an era when healthcare provision shifts away from hospital towards home in order to meet the
603 demands of an increasingly ageing population (Christensen et al., 2009) and the growing burden of
604 chronic diseases (Daar et al., 2007), the contribution of informal caregivers is highly significant.
605 Understanding their needs and challenges is crucial for designing suitable support services within the
606 formal healthcare system and in community settings. The present study shed light in one of these
607 challenges, that is, experiences of loneliness, which should be taken into account when interventions
608 that aim to improve the physical and mental health and quality of life of this population are
609 developed and implemented.

610

611

612 5 Conflict of Interest

613 The authors declare that the research was conducted in the absence of any commercial or financial
614 relationships that could be construed as a potential conflict of interest.

615 6 Author Contributions

616 JB, MB, JV, SL and MW had substantial contribution to the conception of this work. KV and JB
617 designed the study. KV collected and analysed the data and all authors had substantial contribution to
618 the interpretation of the data. KV drafted a previous version of this article and all authors critically
619 revised it for important intellectual input and finally approved of the version to be published. All
620 authors agree to be accountable for all aspects of the work in ensuring that questions related to the
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In review

853 **Table 1:** Caregivers' gender and age by category on the basis of the relationship to the cared-for
 854 person and health status of care recipients

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| Caring for a spouse: $n = 8$ | | |
|---|--|---|
| Gender | Age | Health Status of cared-for person |
| Female (wives) = 3; Male (husbands) = 5 | <i>Mean</i> = 73 <i>Min</i> = 41 <i>Max</i> = 91 | <ul style="list-style-type: none"> • Dementia (6 care recipients) • Multiple sclerosis (1 care recipient) • Osteoarthritis, rheumatoid arthritis and fibromyalgia (1 care recipient) |
| Caring for a parent: $n = 4$ | | |
| Gender | Age | Health Status of cared-for person |
| Female (daughters) = 4 | <i>Mean</i> = 65 <i>Min</i> = 60 <i>Max</i> = 69 | <ul style="list-style-type: none"> • Dementia (1 care recipient) • Physical illnesses and frailty due to old age (3 care recipients) |
| Caring for a child: $n = 3$ | | |
| Gender | Age | Health Status of cared-for person |
| Female (mothers) = 3 | <i>Mean</i> = 51 <i>Min</i> = 46 <i>Max</i> = 59 | <ul style="list-style-type: none"> • Bipolar disorder (1 adult child); • Attention deficit hyperactivity disorder and high functioning autism; • Developmental disorder (1st child) and autism (2nd child) |
| Caring for a partner: $n = 1$ | | |
| Gender | Age | Health Status of cared-for person |
| Female (partner) | 24 years old | <ul style="list-style-type: none"> • Depression and physical illnesses related to infection and the operation of the immune system |

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