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Informal carers' experiences of caring for someone with Multiple Sclerosis: A photovoice investigation

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Objectives. This study explores the lived experiences of carers of people with Multiple Sclerosis (MS), specifically in relation to their quality of life (QoL), through the use of images and narratives, with the aim of gaining a nuanced insight into the complex nature of QoL in the MS caregiving context.

Design. Real-time qualitative design using the photovoice method.

Methods. Twelve MS carers (aged 30–73 years) took photographs of objects/places/ events that represented enhancement or compromise to their QoL and composed written narratives for each photograph based on their experiences of caregiving. In total, 126 photographs and their corresponding narratives were analysed using content analysis.

Results. Seven inter-related themes were identified. MS caregiving-related challenges, sense of loss (e.g., loss of activities), emotional impact (e.g., feeling lonely), urge to escape, and sense of anxiety over the unpredictability of MS carer role were discussed in relation to the negative experiences that compromised their QoL. The themes precious moments (e.g., time spent with loved ones or hobbies) and helpful support (e.g., family and pets) encompassed participants' positive experiences that enhanced their QoL.

Conclusions. Findings demonstrated the multi-faceted and complex nature of MS caregiver's QoL and highlighted that although the experiences of MS carers were mostly negative, there were also some positive aspects to caregiving, that helped enhance carers' QoL by ameliorating these negative experiences. These findings can be used to inform support programmes and enhance service provision for MS carers.

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Statement of contribution
What is already known on this subject?
- Caring for someone with MS can be stressful, affecting quality of life negatively.
- There is a lack of operationalization of quality of life in MS caregiving.
- The issues with operationalization hindered the progress of the current research and practice.

  What does this study add?
- QoL in MS caregiving is a multidimensional concept encompassing both negative and positive aspects.
- MS carers experience several unique obstacles, negative events, and emotions.
- Meaningful activities and support can buffer against negative impact of caregiving, enhancing QoL.

Background

Multiple sclerosis (MS) is a chronic neurodegenerative condition that affects approximately 2.5 million individuals worldwide (MS Trust, 2020). Around 69% of people with MS receive some form of informal care, for which the amount changes considerably with increasing levels of disease severity and disability (Maguire & Maguire, 2020; Thompson et al., 2017). An informal carer is someone who provides voluntary, unpaid support to a family member, friend or a neighbour suffering from an illness, disability, frailty, or mental health problem in order to help them with their daily activities (Carers UK, 2019; Department of Health, 2014). There are approximately 6.5 million carers in the United Kingdom (Carers UK, 2019) and an estimated 34.3% of the population in Europe providing informal care (Verbakel, Tamlagsrønning, Winstone, Fjær, & Eikemo, 2017). Informal caregiving is provided by spouses in up to 70% of people with MS, with remaining of care provided by other family members and friends (Maguire & Maguire, 2020).

Informal caregiving provides many benefits to the health and well-being of people with illness or disability (Alpass, Keeling, Allen, Stevenson, & Stephens, 2017; Jo, Brazil, Lohfeld, & Willison, 2007). In addition, as carers can relieve pressure and financial burden on health care services, there are also societal benefits of informal caregiving (National Academies of Sciences Engineering & Medicine, 2016). In the United Kingdom, the estimated worth of informal care is £132 billion per year, which is considerably more than the total spending on the National Health Service in England (Carers UK, Buckner, & Yeandle, 2015). However, caring for someone with MS can be emotionally and physically demanding and can lead to considerable stress among carers, negatively affecting their health and well-being (Topcu, Buchanan, Aubeeluck, & Garip, 2016). Indeed, there is consistent evidence in the quantitative literature that MS carers' quality of life (QoL) is poor (Corry & While, 2009; Opara & Brola, 2017). Previous studies have demonstrated that high levels of carer burden and anxiety are strongly associated with reduced QoL (Giordano et al., 2016; Opara & Brola, 2017). Severity of MS symptoms (e.g., impaired mobility, bladder problems, cognitive impairment, and depression), increased carer demands, and longer hours of caregiving, are also strong predictors of poor QoL and psychological well-being in MS carers (Buchanan & Huang, 2011; Giordano et al., 2016; Gottberg et al., 2014; Katsavos et al., 2017; Labiano-Fontcuberta, Mitchell, Moreno-García, & Benito-León, 2014; Meca-Lallana et al., 2016; van der Hiele et al., 2019).

However, research into the QoL of MS carers has mostly been based on generic definitions of QoL which have failed to consider disease-specific factors. Indeed, QoL is a complex concept which is difficult to operationalize (Barcaccia et al., 2013; Rapley, 2003). The lack of adequate operationalization and conceptualization limits our ability to

form a sound evidence base in explaining the impact of caregiving (Topcu et al., 2016), obscuring the real effect of interventions. It also makes it difficult to measure MS carers' QoL to identify those who struggle the most, so that resources can be streamlined appropriately.

To maintain a good standard of QoL while providing care and to sustain informal care as an important resource of our health care systems, effective interventions and services are needed to support carers, as well as tools to identify individuals who may require these services. However, much still remains to be done to alleviate negative impact of caregiving on QoL (Topcu et al., 2016). This may partially be related to the lack of a sound evidence base explaining the key factors related to MS carers' QoL and the lack of a comprehensive theoretical framework explaining QoL in MS caregiving. The objective of this exploratory study, therefore, was to derive a more comprehensive understanding of carers' experiences, specifically in relation to their QoL, and to identify factors perceived by informal carers of people with MS as relevant to their QoL. A recent meta-synthesis of qualitative studies in MS caregiving (Topcu et al., 2016) supported the utility of Lazarus and Folkman's (1984) Stress and Coping Model as well as generic caregiving models (e.g., Haley, Levine, Brown, & Bartolucci, 1987; Pearlin, Mullan, Semple, & Skaff, 1990) in explaining caregiving in MS, as these models comprised similar constructs (e.g., stressors and coping resources). However, these generic models fail to consider some of the disease-specific factors (e.g., MS-related challenges and unpredictability of MS) which may be important in explaining MS caregiving experiences.

Qualitative studies are increasingly recognized as an important source of evidence for person-centred health care research and practice (Hayre & Muller, 2019; Yardley, Morrison, Bradbury, & Muller, 2015) and are considered important in operationalizing complex concepts and enhancing theoretical understanding of processes (Craig et al., 2013). Although there are many qualitative studies examining the experiences of MS carers (e.g., Gafari, Khoshknab, Nourozi, & Mohamadi, 2017; Golla, Mammeas, Galushko, Pfaff, & Voltz, 2015; McCurry, 2013; Rollero, 2016), yet none of these have looked specifically at QoL (Topcu et al., 2016). In particular, there is a lack of research undertaking participatory approaches that empowers and engages MS carers (Bergold & Thomas, 2012). Therefore, the aim of our study was to explore the lived experiences of informal carers of people with MS, specifically in relation to their QoL, through the use of images and narratives. This may give us a more nuanced insight into the complex nature of their QoL and help operationalize the definition of QoL in the MS caregiving context. This, in turn, can provide a better understanding of the factors that can be targeted while designing interventions to support MS carers. It may also facilitate the development of reliable and valid disease-specific QoL questionnaires to quantify MS carers' experiences of caregiving related to their QoL to identify those who need support.

Methods

Epistemology
We adopted a critical realist stance, which assumes the existence of objective realities independently of our perceptions, theories, and constructions and recognizes that the ability to access this in reality is tentative (Harper, 2012; Maxwell, 2012). In line with this, we assumed that carers' sense making of their QoL in relation to their caregiving role was subjective and constructed; however, there is a physical and objective reality to these caregiving experiences. We also adopted a person-centred approach (Yardley et al., 2015)

to gain vital insights into MS caregiving from the perspective and psychosocial context of the MS carers.

Design

In order to provide an in-depth exploration of factors salient to the QoL of informal carers of people with MS, the photovoice method was employed due to its potential for offering new insights into the complex nature of QoL issues in caregiving (Aubeeluck & Buchanan, 2006). Participants had the opportunity to explore the concept of QoL by photographing and giving written reflections on specific QoL issues surrounding their MS caregiving experiences in a *real-time* manner (i.e., capturing experiences as they happen as participants go through their daily lives, rather than asking them retrospectively). Photovoice is a participatory visual research method in which participants are asked to create their own visuals (e.g., photographs, videos) to capture their individual perspectives on health and illness; they are then given the opportunity to reflect on the content of these visuals (Lorenz & Kolb, 2009; Wang & Burris, 1997). It is often used in health care research to identify and explore community or individual perspectives on health-related concepts/behaviours, assess health needs, and examine person-environment interactions (Topcu, 2015). Photovoice enables individuals to focus on their experiences, concerns, and needs and provides a powerful means of communication of these issues to health care providers and policymakers (Wang, 1999; Wang & Burris, 1997). Photovoice can be used within a critical realist framework, as the photographs can help capture participant's experiences (i.e., realities) in a way that is richer than words alone and enables interpreting this reality in a subjective and collaborative way. It also fits well with our person-centred approach as it allows participants to share their own realities from their own perspective by empowering them to focus on what is of value to them.

Participants

Individuals aged over 18 years, who were providing unpaid and voluntary care for a relative or a friend with MS, and who were able and willing to give informed consent were eligible to participate. In total, 20 carers volunteered to participate; however, eight of these withdrew (the main reason was time constraints) leaving 12 participants (aged 30–73 years; seven females) with which critical mass of data was achieved ensuring rigour in analysis (Wang, 1999). Participants were recruited through the MS Society United Kingdom ($n = 2$), North Cyprus MS Association ($n = 2$), online support groups for people with MS and their carers (e.g., MS Trust, Carers UK Facebook pages) ($n = 3$) and by word-of-mouth ($n = 5$).

The mean number of years of informal caregiving was 10.25 years ($SD = 5.75$). Majority of carers were married ($n = 8$), two were single, and two were divorced. Eight were spouses/partners; three had a parent with MS; and one was a friend. Five carers reported having a medical condition themselves (e.g., heart problems, diabetes, back problem, and migraine).

Materials and procedures

All participants were provided with written information concerning the purpose of the study, confidentiality, and their rights as a participant in the research process. After obtaining participants' written consent and explaining the photovoice procedure,

participants were also provided with an instruction sheet which gave a detailed description of the steps to follow during the study. In order to provide some context to the participants, the instruction sheet included a written description of three definitions of QoL (The WHOQOL Group, 1995; Cummins, 1997; Ferrans, Zerwic, Wilbur, & Larson, 2005). These definitions were chosen because they are considered to be the most accepted definitions of QoL including both objective and subjective elements (Bakas et al., 2012). However, participants were also advised that QoL was whatever they felt it meant to them as an individual and that they might have their own definition. They were also given examples of photographs with corresponding narratives (of an unrelated topic) in order to put the photovoice process in context.

Participants were given the option of using their own digital cameras or smartphones to take photographs ($n = 10$), or a disposable 27-exposure, colour-film cameras provided to them ($n = 2$). They were asked to take 10–15 photographs of things/places that represent a compromise or enhancement of their QoL and of things/places that best reflect their experiences as carers of people with MS. Carers were told that it did not matter if they took more pictures of enhancing rather than compromising things or vice versa.

Participants were asked to label each photograph and write a corresponding narrative straight after taking it or as soon as possible. A corresponding dialogue sheet was provided for participants to write their reflections on why they took the photograph and what it meant to them at the time of taking it. They were also asked to write briefly about its impact on their QoL. Participants had 2 weeks to take the photographs, write the corresponding narratives, and return to us.

Ethical considerations

Ethical approval was obtained from the first author's institution. Although carers were asked not to photograph people, some did take photographs of family members and friends. Those photographs were destroyed after the analysis, but their corresponding narratives were kept for the dissemination. Written consent was also obtained from participants for publication of pictures and their associated narratives. Participants were debriefed after completion of the study, and contact information on appropriate resources was provided in case they needed further information/support with respect to MS caregiving. All participants are referred to by pseudonyms.

Data analysis

One hundred and twenty-six descriptively labelled photographs and their corresponding narratives were analysed using Content Analysis (Weber, 1990), which is considered to be an appropriate approach to analyse this type of data (Aubeeluck & Buchanan, 2006; Budig et al., 2018) from a critical realist stance (Fletcher, 2017; Leung & Chung, 2019). Content analysis of photovoice data elucidates nuances and enhances elaboration of themes and categories to create valid inferences generating knowledge that can be utilized in practice (Faucher & Garner, 2015). Analysis was initially undertaken, using an inductive approach, by the first author who is an experienced qualitative researcher with expertise in MS. Photographs and narratives were analysed together to identify manifest content, a process directed at identifying obvious and meaningful components (i.e., coding) within the photographs or narratives that expressed a compromise or an enhancement to QoL. Identified components that described reoccurring commonality were then categorized,

and the researchers met to discuss and clarify categories which lead into the identification of themes. In order to make the coding process transparent and reproducible, a coding manual was developed including the emerging codes and categories, their descriptors, and example narratives and photographs (see Appendix S1). The final coding manual was reviewed and discussed by the wider research team alongside narratives and photographs to enhance the credibility and rigour of research findings and also to ensure the accuracy and relevancy of themes. Analysing photographs and narratives together enhanced the credibility of our findings and enabled tentative latent inferences in relation to the photographs, as some of the photographs were symbolic representations of experiences (i.e., without the narrative, it would be difficult to depict the meaning behind the symbolic form). To ensure intersubjectivity of the coding process and enhance the credibility of the findings (Burla et al., 2008; O'Connor & Joffe, 2020), a second coder also coded each photograph and narrative independently, using the final coding manual. Inter-coder reliability was calculated by Cohen's Kappa. In addition, we applied Yardley's (2000) evaluative characteristics for good qualitative research. To ensure transparency and quality of reporting, we have followed the APA Journal Standards of reporting for qualitative and mixed-methods research (Levitt et al., 2018), as recommended by Shaw and colleagues (Shaw, Bishop, Horwood, Chilcot, & Arden, 2019).

Results

Participants took 126 photographs in total, with a median of 11 per person ($M = 10.50$, range 2–15). These were categorized into seven inter-related themes relating to QoL issues for MS carers. Table 1 presents the frequencies of the seven themes extracted from the data; multiple themes were often extracted from each photograph and their narratives, and thus, the frequency refers to the occurrence of the themes rather than per photograph. The kappa coefficient was .86 (95% CI, 0.810 to 0.912, $p < .001$), indicating a high level of agreement between coders (Landis & Koch, 1977).

Challenges and troubles
The most frequent theme, highlighted by 11 participants, was 'challenges and troubles', that encompassed both the MS-related and caring-related challenges the carers faced. In particular, difficulties faced due to MS symptoms were mentioned in the narratives by six participants. They took several photographs of syringes, medicines, and wheelchairs to demonstrate how MS and the associated caring issues impacted on their QoL. For instance, one participant described how it was difficult to have a conversation with his wife while

Table 1. Frequencies of the themes extracted from the photovoice data

Themes	Number (%)
Challenges and troubles	39 (19.8)
Sense of loss	38 (19.3)
Emotional impact of caregiving	34 (17.3)
Escape	17 (8.6)
Unpredictability of MS	14 (7.1)
Precious moments	34 (17.3)
Helpful support	21 (10.7)

pushing the wheelchair. He sees the wheelchair as 'a symbol of dependency' that confirms his carer role. He accompanied the quote below with a photograph of his wife's wheelchair (Figure 1).

> It is difficult to have a conversation when propelling a wheelchair you cannot see the sitter's face and you do have to be aware of the pavement or flooring conditions. A wheelchair is a common sight, but few people need to think about the pusher or the passenger. In a sense a wheelchair is liberty for the passenger that can be a problem for others. To me it confirms the position of carer. No wheelchair, no means of getting from A to B. It is also a symbol of dependency. (Peter, aged 73, caring for his spouse)

Daily hassles and other responsibilities (e.g., housekeeping) and the physical barriers (e.g., limited access for wheelchairs, stairs, difficulty in manoeuvring around the inside of shops) were also commonly described by many participants ($n = 10$) as a major compromise to their QoL.

Sense of loss

The next most common theme which was highlighted by eleven participants was 'sense of loss' in carer's lives. Majority of the participants ($n = 9$) referred to losses of personal activities or shared activities caused by the MS symptoms (e.g., loss of motor skills, fatigue, pains) or by the lack of time due to additional caregiving duties, which constrained their engagement in activities or attendance at social occasions.

Environmental barriers for people with disabilities also caused some carers to stay at home instead of attending social occasions together with their care recipients. For instance, one participant took a photograph of a local pub to represent the loss of a social activity he used to engage in due to the environmental barriers and practical constraints.

> I like real ale and old pubs. Unfortunately can't go to many with my partner as they usually have toilets that are difficult to get into with a wheelchair as they don't have disabled toilets which means I miss out on something I like to do. (Patrick, aged 52, caring for his partner)

Four participants described not having enough time to do the things they like or to relax. Three of them took pictures of clocks and sandglass while another participant took a

Figure 1. The Wheelchair of participant's wife denoting the challenges and barriers.

picture of a hair salon to demonstrate that she did not have enough time to care for herself (Figure 2). The quotes below explain the negative impact of lack of time on their QoL.

> [...] no time to enjoy life and do the things that I actually like, no time to relax... It's all about having the time! If you don't have enough time then there is no quality of life... (Emma, aged 37, caring for her spouse)
>
> The time is simply not enough. Working full-time, caregiving and other responsibilities at home don't leave me much time to do the things that I like, which can be a little frustrating at times (Matt, aged 35, caring for his spouse)

Loss of health and well-being were also reported by three carers due to the increased responsibilities and burden. One carer took a picture of her painkillers to demonstrate her physical aches and pains. She took another picture of a broken branch of a tree as a symbolic representation for her feelings of being 'broken' due to losing her job and breaking up with her husband after becoming a carer for her mother with MS.

Five participants reported loss of identity as they had to stop working to become the carer or change their lifestyle, for example not being as socially active as before. Participants also reported feelings of frustration due to the loss of spontaneity in their lives and postponing future plans (e.g., having a baby).

Another interesting finding was that male participants took more photographs that represented the loss of activities they experienced than female participants, suggesting that men's diminished QoL may be more likely to be related to the changes and losses in their social lives due to MS and their caring role. On the contrary, women reported more

Figure 2. A photograph of a hair dresser denoting the lack of time for taking care of own needs.

health- and well-being-related and identity-related losses than men, suggesting that women may be more perceptive to their internal changes rather than the external and social changes.

Emotional impact of caregiving

This theme encompassed a wide range of negative emotions highlighted by ten participants as compromising their QoL. Five participants reported feelings of hopelessness as there is no cure for MS. They reported feeling helpless, useless, and powerless as they have no control over the disease. One carer expressed his feelings of helplessness, despair, and anger towards medical science by referring to a news report about war (Figure 3).

> They make all kinds of weapons for wars. They've developed the technology to destroy a whole territory by only pressing a button. Mankind can even travel to the space now. Why is there still no cure for this disease? Why can't we do anything? Why has the medical science failed to invent a cure for this disease? (George, aged 54, caring for his spouse)

Some participants felt loneliness due to isolation and lack of support from other family members or friends. Furthermore, seeing the care-recipient suffer made carers upset and sad. One participant expressed her feelings by taking a picture of flowers in the garden (gardening, an activity her care-recipient friend used to do pre-MS):

Figure 3. A news report about war as a symbolic representation for emotional impact of caregiving.

> It makes me sad to think that she lost her spirit and is less interested in her environment now. It's heart breaking to witness her silence and low mood. (Cathy, aged 64, caring for her friend)

Majority of carers ($n = 8$) were worried about the possibility of losing their care recipients, the possible future progression and deterioration of the illness, and the impact of this on their own QoL.

> I'm always concerned about my mother. What if she gets worse or never gets well? (Susan, aged 33, caring for her parent)

> I get worried about the possibility of her getting worse (George, aged 54, caring for his spouse)

Participants reported feeling worried about the future and their families. One carer expressed her worries with the following quote and image (Figure 4).

> I worry sick every time one of my kids complain of pins and needles or tingling and numbness in their bodies. I can't handle if they have MS too. (Jennifer, aged 46, caring for her parent)

Escape

Thoughts of escaping the caregiving role and the difficult situations due to MS was another common theme highlighted by majority of participants ($n = 8$). However, it was clear from their narratives that such escape was not an option for them. Two participants also
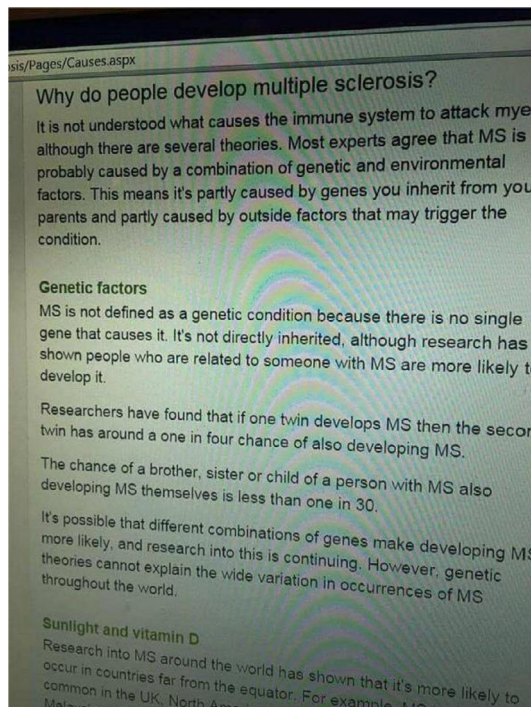
Figure 4. An article on an NHS webpage on carer's computer screen denoting the worry she felt about the possibility of her children becoming MS.

felt trapped in their homes with no escape. One participant took a photograph of a plane to demonstrate the urge she felt to escape (Figure 5).

> Sometimes, I want to get away from all these problems. To go to a place far away where there is no suffering or pain, only happiness. I wish I could just get on this plane and fly away to places unheard. (Jennifer, aged 46, caring for her parent)

Six participants also reported engaging in several different activities (e.g., reading, gambling, walking the dog, listening to music) as a way of escaping the reality of caregiving even if it was for a short time.

> My books. My way of escaping the reality. . . (Jennifer, aged 46, caring for her parent)

Unpredictability of MS
Frustration with the unpredictability of MS and the future was brought up by several participants ($n = 8$). They found it difficult to deal with which often provoked anxious thoughts.

> MS is a mystery disease. Everything about it is unpredictable and it's terrifying. (Emma, aged 37, caring for her spouse)

To express their feelings about unpredictability, participants either used images of sky or sea which symbolized the uncertainty and the unknown beyond the clouds or the horizon. One carer took a photograph of a grey sky with heavy dark clouds (Figure 6) and compared the unpredictability of MS with that of the weather, concluding that the unpredictability of MS is more difficult to deal.

> They say nothing is as unpredictable as the weather. They have never been so wrong! (Matt, aged 35, caring for his spouse)

Two participants took pictures of question marks to demonstrate the future possibilities or the unanswered questions about the MS.

Figure 5. A plane denoting the need to escape.

Figure 6. A grey cloudy sky representing the unpredictability of MS.

> A question mark in a large square – is to me a mixture of both positive and negative possibilities. The former reflecting many more happy years, the latter a more troubled future. (Peter, aged 73, caring for his spouse)

Precious moments

Although the carers took more photographs of things or places that represented compromise to their QoL (72%), majority also touched on things that enhanced their QoL with images capturing these positive experiences in their lives. There were only two carers (a 52-year-old male carer and a 37-year-old female carer) with no positively themed photographs.

Ten participants took pictures of moments spent with loved ones, as well as places or things representing the time spent on hobbies and meaningful and positive activities. Carers expressed such moments as 'precious' as these moments were rare but highly cherished. They also took photographs of things that helped them manage the caring role thus enhancing their QoL. Carers relished moments of peace and happiness as these enriched their lives. For instance, one carer took a photograph of her yoga spot (Figure 7) where she practiced yoga for 3 hrs a week which was a very important activity for her. She expressed feeling 'rusty, breathless and weak' when she couldn't do her yoga and added:

> The only spot, where I feel peaceful, strong, in balance and entirely alive. (Rachel, aged 30, caring for her parent)

Gardening and taking care of flowers were frequently mentioned positive activities that participants found very relaxing and fulfilling:

> I love growing plants from cuttings and seeds. I find it very relaxing and fulfilling. [. . .] It is quite time consuming, but my wife often sits near the greenhouse (weather permitting) and we talk with plants. I do like the sense of renewal, seeds are sown and plants set to produce a new scene each year, some are not always successful, but overall life goes on. Looking out of the window I can enjoy the fruits of my labour. (Peter, aged 73, caring for his spouse) (See Figure 8).
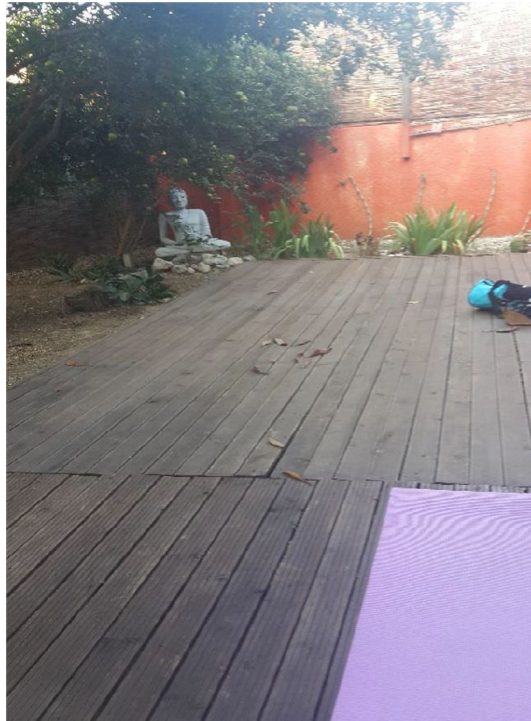
Figure 7. A yoga spot denoting a precious moment in carer's life.

Figure 8. A greenhouse denoting enhancement to carer's QoL.

Helpful support

Support was another theme that encompassed participants' positive experiences enhancing their QoL. Five carers took photographs of the things that represented their family members or friends (e.g., A Mother's Day card, flowers from husband). The following quote and Figure 9 demonstrates how much the support from a family member meant to this carer.

> My daughter has become my greatest support over the last few years. It's a blessing to have her in my life. (Jennifer, aged 46, caring for her parent)

Half of carers took pictures of their dogs to demonstrate how the unconditional love received from their pets impacted on their QoL in a positive way while caring for someone with MS. They referred to their dogs as their friends and they saw them as part of the family. It is apparent that their presence played an important part in their lives in a very positive way. One carer who took a photograph of her dog (Figure 10) described how he has become an important source of support for all the family members:

> We adopted this dog from an animal shelter when my husband's condition had gone worse, hoping that it would boost our spirits. We thought we saved him, but it turned out that he is the one who has saved us all:)) He is one of our true friends now! (Lisa, aged 32, caring for her spouse)

Two carers also reported receiving help from support groups for people with MS and their carers. Some carers described how they found reading books about MS and using the information technologies as useful resources to understand MS. Some also described the positive impact of the Internet in terms of socializing with their friends as they did not have time for going out anymore.

It should be noted that some participants were dissatisfied with the support received from formal resources. These photographs and their corresponding narratives were either categorized into the 'challenges and troubles' or into the 'emotional impact of caregiving'

Figure 9. A card from carer's daughter denoting helpful support.

Figure 10. A dog denoting a source of helpful support.

themes. Therefore, the theme 'helpful support' in this study only refers to the positive experiences of MS carers.

Discussion

There were seven inter-linking themes identified that appeared to be intrinsically related to MS carers' QoL. Five of these reflected negative experiences that participants reported as having a negative impact on their QoL. For instance, challenges related to caregiving and MS were described as a compromise to carers' QoL. This supports quantitative studies showing that MS symptoms, caregiving demands, environmental and financial barriers are significant predictors of carer burden and poor QoL (Akkus, 2011; Alshubaili, Ohaeri, Awadalla, & Mabrouk, 2008; Buhse, Ratta, Galiczewski, & Eckardt, 2015; van der Hiele et al., 2019; Katsavos et al., 2017; Rivera-Navarro et al., 2009). Participants also frequently reported missing out on social activities and having poorer health due to MS caregiving which appeared to play an important role in their QoL. Similarly, Borreani et al. (2014) found that one of the most prominent unmet needs of MS carers were social activities and leisure time. They also found that carers were more likely to pay less attention to their own needs and health due to the lack of time.

It was evident that MS carers experienced negative emotions related to their caregiving roles and responsibilities. Carers frequently expressed feelings of sadness, helplessness, hopelessness, and loneliness. Such feelings are frequently reported in studies with MS carers and have been consistently associated with decreased well-being and life satisfaction and increased depressive symptoms (Corry & While, 2009; Petrikis, Baldouma, Katsanos, Konitsiotis, & Giannopoulos, 2019). Worries about the care-recipient, other family members, and themselves (e.g., fear of them developing MS), and the future were also prominent in the current study. On a similar note, Alshubaili et al. (2008) reported that fear of having MS among MS carers was associated with low QoL scores.

The need for 'escape' from caregiving responsibilities and associated negative feelings were also evident. Carers commented that they wanted to run away from the difficulties of being a carer; however, they also felt that there was no way out from their caregiving role which is consistent with the literature (Petrikis et al., 2019). Previous studies

demonstrated that caring for someone with MS imposes stress and intolerable burden on the carer (Corry & While, 2009; Petrikis et al., 2019; Topcu et al., 2016), which may explain carers' urge to escape. One study highlighted that the need for 'space' was associated with the demands of caregiving, and carers described the need to get away from caregiving as a central feature of coping with the constant tension and stress (DesRosier, Catanzaro, & Piller, 1992). Similarly, carers in our study took photographs of activities they did to escape from the demands of their responsibilities which suggests that some carers use escape as a coping mechanism to buffer the negative impact of MS caregiving on their QoL.

'Unpredictability' was another theme which encompassed feelings of uncertainties about the progress of MS and the future which negatively affected their QoL. Uncertainty is a prominent part of living with MS (Wilkinson & das Nair, 2013). Thus, it was not surprising that carers felt that their responsibilities, routines, and capacity for engaging in everyday activities were affected by the unpredictable course of MS. Previous studies with people with MS showed that the unpredictable disease course and consequences of MS were a great source of distress which might lead to anxious thoughts and depressive symptoms (Bruce & Arnett, 2009; McCabe, Ebacioni, Simmons, McDonald, & Melton, 2015; du Plooy & Pretorius, 2014; Topcu et al., 2016; Wilkinson & das Nair, 2013). However, the possible link between unpredictability and MS carer QoL was unique to this study and warrants further investigation to understand the direction and strength of this relationship.

The use of photovoice methodology enabled participants to record the positive aspects in their lives and reflect on factors that enhanced their QoL. The theme 'precious moments' encompassed positive activities and features, such as time spent on their hobbies or with their loved ones. Carers greatly valued such times as they were rare due to their busy and stressful lives. This theme is similar to the concept of 'daily uplifts' introduced by Kanner, Coyne, Schaefer, and Lazarus (1981) which refers to the small positive experiences that evoke pleasure, affirmation, and joy in the person (e.g., manifestations of love, engaging in a favourite activity). They suggested that these uplifts may buffer individuals against the negative impact of daily hassles. Dementia caregiving literature demonstrated uplifts as being highly relevant to the well-being of dementia carers (Kinney & Stephens, 1989; Lawton, Kleban, Moss, Rovine, & Glicksman, 1989). However, the theme 'precious moments' was not readily identifiable in the MS caregiving literature. This could be related to the instructions that were given to our participants (i.e., taking photographs of things that enhance or compromise their QoL). As such, photovoice provided a unique opportunity for carers to record and reflect upon, not only the negative aspects of their lives, but also their positive experiences that influence their QoL. This was useful in terms of gaining a more holistic picture of MS caregiving.

A further theme that reflected carers' positive experiences was 'helpful support'. Most participants expressed their satisfaction with the support they were receiving from their family or friends. However, a recent meta-synthesis showed that the level of satisfaction with the informal support varied among the carers, drifting towards the negative side (Topcu et al., 2016). Interestingly, photovoice participants did not express any dissatisfaction with the informal support resources. These inconsistent findings could be explained by the social desirability effect (Kaminska & Foulsham, 2013). It is possible that carers underreported their feelings of dissatisfaction towards the support provided by their relatives/friends and did not want to admit that they felt unhappy or frustrated with their loved ones for not providing any/enough support. The self-selection sampling method may also produce bias in the sample. As such, it is possible that those who

consented to take part might be better adjusted to their caregiving roles than those who did not participate, as adjustment problems might be related to lower levels of perceived social support (Dayapoğlu & Tan, 2017; Pakenham, 2001). Alternatively, the inconsistent findings with regard to the informal support could result from the presence of visual element in the study. Neuropsychological studies showed that seeing a loved one can elicit positive emotions by activating reward-related regions in the brain and can lead to feelings of elation (e.g., Bartels & Zeki, 2004; Esch & Stefano, 2005; Matsunaga, Yamauchi, Nogimori, Konagaya, & Ohira, 2008). Additionally, Master et al. (2009) found that simple reminders of loved ones (e.g., photographs) may prime mental representations of being loved and supported, reducing experiences of pain. Thus, carers' feelings of love and commitment might intensify upon seeing reminders of loved ones while reflecting on the photographs they took, leading to focus more on positive aspects of their relationships and ignore the negative thoughts about the support received. Future research needs to explore the effects of photovoice to understand whether seeing representations of experiences might intensify certain feelings or not.

This study also highlighted how pet ownership can act as a support system for MS carers. This was not previously reported in MS caregiving literature. However, it should be noted that some participants might be biased by the example photograph provided in the instruction sheets (i.e., one example photograph was an image of a dog, although its corresponding narrative was not related to MS caregiving). However, each participant who took photographs of their pets explained their own unique experiences and expressed their own feelings about their pets in their own words. Moreover, the positive impact of pet ownership on QoL has also been reported in another photovoice study with women affected by polycystic ovary syndrome which has shown that having a pet may enhance women's quality of life (Williams, Sheffield, & Knibb, 2014). Similarly, previous research demonstrated the supportive roles of pets showing that pet owners perceive their pets as their companions who provide a broad range of beneficial effects on their health and well-being, such as improved emotional state, reduced sense of loneliness and depressive symptoms, and improved cardiovascular functioning (Allen, Blascovich, & Mendes, 2002; Antonacopoulos & Pychyl, 2010; Bonas, McNicholas, & Collis, 2000; McConnell, Brown, Shoda, Stayton, & Martin, 2011; Stanley, Conwell, Bowen, & van Orden, 2014). However, a recent review also showed that 'pet-effect' research is inconclusive as empirical studies have produced conflicting results with regards to the impact of pet ownership on human health and well-being (Herzog, 2011). Antona-copoulos and Pychyl (2010) argued that the relationship between pet ownership and well-being is complex in nature and more high-quality research is needed to be able to fully understand this relationship (Herzog, 2011; Peacock, Chur-Hansen, & Winefield, 2012).

Our findings present novel conceptual insights to MS carers' QoL which can be used to generate new theoretical models or adapt existing ones to explain QoL in the MS caregiving context, and suggest that a more holistic conceptualization of QoL is needed to guide empirical research and practical efforts to better support MS carers. The impact of caregiving on QoL may be considered within the conceptual definitions of lifeworld-led care (Todres, Galvin, & Dahlberg, 2006), a model previously used in the context of caregiving (Ashworth, 2006) and understanding QoL (Aston, Shaw, & Knibb, 2019). The lifeworld is a holistic outlook in which individuals make sense of the world in relation to time, space, body, others, and mood (Todres et al., 2006). In our study, participants' accounts seem imbued with dimensions of the lifeworld: temporality (i.e., *sense of loss and unpredictability of MS*), spatiality (i.e., *escape*), intersubjectivity (i.e., *precious moments* and *helpful support*), embodiment (i.e., *challenges and troubles*), and mood

(i.e., *emotional impact of caregiving*). Future research should examine the utility of lifeworld framework in more detail in explaining the impact of MS caregiving on QoL.

Limitations and strengths

Attrition was high as in previous photovoice studies (e.g., Williams et al., 2014). One possible explanation may be the number of steps participants had to complete (e.g., the process of writing narratives to express the meaning behind the photographs, choosing which photographs to take) which included complex and burdensome procedures for some (Baker & Wang, 2006) considering carers' busy and stressful schedules (Topcu, 2015). To make the process less challenging, we requested participants to take 10–15 photographs, rather than taking 27 pictures (i.e., number of exposure in a disposable camera).

Participants were given a definition of QoL at the beginning of the study to provide some context for the research; this may have limited the participants' conceptualization of their own definition of QoL. However, we also advised participants that QoL was whatever they felt it meant to them as an individual and that they might have their definition. It was hoped that this would minimize the risk of biasing the findings. This study is also limited by its small convenience sample. However, our sample size ($N = 12$) exceeds the recommended sample size for this type of methodology which is usually around 7-10 participants (Wang, 1999). In addition, the study recruited participants from social support groups, and therefore, these individuals may have unique characteristics to these social communities which could limit the generalizability.

The use of photovoice methodology created a unique opportunity for carers to capture events over a 2-week period and reflect on issues related to their QoL as they arose. This represents more than a 'snapshot' in time and enabled us to explore carers' experiences in a real-time fashion (Topcu, 2015). In addition, photovoice is a 'concrete way for people to communicate their vision and voice' (Wang & Burris, 1994, p.173). Therefore, the objective photographs taken by the participants, combined with their subjective accounts of the meaning behind the photographs, provided an insight into their realities and private lives. Photovoice also fits in well with the person-centred approach which is increasingly being used in research and intervention development (Yardley et al., 2015), as the use of visual images and the messages behind the photographs offer 'the possibility of perceiving the world from the viewpoint of the people' (Ruby 1991, p. 50, as cited in Wang & Burris, 1997).

Moreover, photovoice provided access to experiences that might otherwise be overlooked or missed for being too difficult to articulate or too abstract (Frith & Harcourt, 2007). Participants may sometimes have difficulty in expressing certain feelings or experiences during an interview (Topcu, 2015), whereas the use of photographs can help capture such complex emotions and experiences (Frith & Harcourt, 2007). However, it is also not always possible to capture experiences in a visual image (Topcu, 2015); thus, the corresponding narratives were equally important and informative (Frith & Harcourt, 2007; Topcu, 2015). Overall, the combination of photographs and their corresponding narratives allowed participants to express their feelings, thoughts, and experiences through a variety of symbolic, abstract, or more concrete forms, corroborating the credibility of our findings (Frith & Harcourt, 2007).

Photovoice also produced several types of data (e.g., photographs and narratives), enabling data triangulation (Catalani & Minkler, 2010). Analysing both photographs and corresponding narratives enhanced the credibility and trustworthiness of our findings, as

the photographs provided both evidence and validation for shared concerns of participants which were conveyed through the narratives (Wang & Burris, 1994).

Conclusion

The use of the photovoice method provided a unique opportunity for carers to capture and reflect on factors that impacted on their QoL as they arose. Our findings shed new light into the complex and multidimensional nature of QoL and highlight that although the impact of MS on carers' QoL was mostly negative, there were also positive aspects to caregiving such as uplifting positive experiences and the supporting role of loved ones that helped buffer against these negative factors and enhance QoL. Further exploration of these themes is essential for corroboration of the potentially important issues in MS carer QoL, so that appropriate assessment tools and support services can be developed. Our findings demonstrate the importance of providing emotional and practical support services for carers focusing on reducing the impact of stressors by focusing on helpful coping and support resources.

Acknowledgements

Conflicts of interest

All authors declare no conflict of interest.

Author contributions

Gogem Topcu, Ph.D., M.Sc., B.Sc. (Hons) (Conceptualization; Data curation; Formal analysis; Investigation; Methodology; Project administration; Resources; Software; Validation; Visualization; Writing – original draft; Writing – review & editing) Heather Buchanan (Conceptualization; Formal analysis; Methodology; Resources; Supervision; Validation; Writing – original draft; Writing – review & editing) Aimee Aubeeluck (Conceptualization; Formal analysis; Methodology; Supervision; Validation; Writing – original draft; Writing – review & editing) Hatice Ülsever (Formal analysis; Software; Validation; Writing – original draft; Writing – review & editing).

Data availability statement

The data that support the findings of this study are available from the corresponding author upon reasonable request.

References

Akkus, Y. (2011). Multiple Sclerosis patient caregivers: The relationship between their psychological and social needs and burden levels. *Disability and Rehabilitation*, *33*(4), 326–333. https://doi.org/10.3109/09638288.2010.490866

Allen, K., Blascovich, J., & Mendes, W. B. (2002). Cardiovascular reactivity and the presence of pets, friends, and spouses: The truth about cats and dogs. *Psychosomatic Medicine*, *64*, 727–739. https://doi.org/10.1097/01.PSY.0000024236.11538.41

Alpass, F., Keeling, S., Allen, J., Stevenson, B., & Stephens, C. (2017). Reconciling work and caregiving responsibilities among older workers in New Zealand. *Journal of Cross-Cultural Gerontology*, *32*(3), 323–337. https://doi.org/10.1007/s10823-017-9327-3

Alshubaili, A. F., Ohaeri, J. U., Awadalla, A. W., & Mabrouk, A. A. (2008). Family caregiver quality of life in Multiple Sclerosis among Kuwaitis: A controlled study. *BMC Health Services Research*, *8*, 1–9. https://doi.org/10.1186/1472-6963-8-206

Antonacopoulos, N. M. D., & Pychyl, T. A. (2010). An examination of the potential role of pet ownership, human social support and pet attachment in the psychological health of individuals living alone. *Anthrozoös*, *23*(1), 37–54. https://doi.org/10.2752/175303710X12627079939143

Ashworth, P. D. (2006). Seeing oneself as a carer in the activity of caring: Attending to the lifeworld of a person with Alzheimer's disease. *International Journal of Qualitative Studies on Health and Well-being*, *1*(4), 212–225. https://doi.org/10.1080/17482620600967786

Aston, L., Shaw, R., & Knibb, R. (2019). Preliminary development of proxy-rated quality-of-life scales for children and adults with Niemann-Pick type C. *Quality of Life Research*, *28*, 3083–3092. https://doi.org/10.1007/s11136-019-02234-5

Aubeeluck, A., & Buchanan, H. (2006). Capturing the Huntington's disease spousal carer experience: A preliminary investigation using the 'Photovoice' method. *Dementia*, *5*(1), 95–116. https://doi.org/10.1177/1471301206059757

Bakas, T., McLennon, S. M., Carpenter, J. S., Buelow, J. M., Otte, J. L., Hanna, K. M., . . . Welch, J. L. (2012). Systematic review of health-related quality of life models. *Health and Quality of Life Outcomes*, *10*, 134. https://doi.org/10.1186/1477-7525-10-134

Baker, T. A., & Wang, C. C. (2006). Photovoice: Use of a participatory action research method to explore the chronic pain experience in older adults. *Qualitative Health Research*, *16*, 1405–1413. https://doi.org/10.1177/1049732306294118

Barcaccia, B., Esposito, G., Matarese, M., Bertolaso, M., Elvira, M., & De Marinis, M. G., (2013). Defining quality of life: a wild-Goose chase? *Europe's Journal of Psychology*, *9*(1), 185–203. https://doi.org/10.5964/ejop.v9i1.484

Bartels, A., & Zeki, S. (2004). The neural correlates of maternal and romantic love. *NeuroImage*, *21*, 1155–1166. https://doi.org/10.1016/j.neuroimage.2003.11.003

Bergold, J., & Thomas, S. (2012). Participatory research methods: A methodological approach in motion. *Historical Social Research/Historische Sozialforschung*, *37*, 191–222.

Bonas, S., McNicholas, J., & Collis, G. M. (2000). Pets in the network of family relationships: An empirical study. In A. L. Podberscek, E. S. Paul & J. A. Serpell (Eds.), *Companion animals and us* (pp. 209–236). Cambridge, UK: Cambridge University Press.

Borreani, C., Bianchi, E., Pietrolongo, E., Rossi, I., Cilia, S., Giuntoli, M., . . . Solari, A. (2014). Unmet needs of people with severe Multiple Sclerosis and their carers: Qualitative findings for a home-based intervention. *PLoS One*, *9*(10), e109679. https://doi.org/10.1371/journal.pone.0109679

Bruce, J. M., & Arnett, P. (2009). Clinical correlates of generalized worry in multiple sclerosis. *Journal of Clinical and Experimental Neuropsychology*, *31*(6), 698–705. https://doi.org/10.1080/13803390802484789

Buchanan, R. J., & Huang, C. (2011). Health-related quality of life among informal caregivers assisting people with multiple sclerosis. *Disability and Rehabilitation*, *33*(2), 113–121. https://doi.org/10.3109/09638288.2010.486467

Budig, K., Diez, J., Conde, P., Sastre, M., Hernán, M., & Franco, M. (2018). Photovoice and empowerment: Evaluating the transformative potential of a participatory action research project. *BMC Public Health*, *18*(1), 432. https://doi.org/10.1186/s12889-018-5335-7

Buhse, M., Ratta, C. D., Galiczewski, J., & Eckardt, P. (2015). Caregivers of older persons with Multiple Sclerosis: Determinants of health-related quality of life. *Journal of Neuroscience Nursing*, *47*(2), E2–E12. https://doi.org/10.1097/JNN.0000000000000117

Burla, L., Knierim, B., Barth, J., Liewald, K., Duetz, M., & Abel, T. (2008). From text to codings: Intercoder reliability assessment in qualitative content analysis. *Nursing Research*, *57*(2), 113–117. https://doi.org/10.1097/01.NNR.0000313482.33917.7d

Carers UK. (2019). *Facts about carers*. Retrieved from https://www.carersuk.org/images/Facts_about_Carers_2019.pdf

Carers UK, Buckner, L., & Yeandle, S. (2015). *Valuing Carers 2015: The rising value of carers' support*. Retrieved from https://www.sheffield.ac.uk/polopoly_fs/1.546409!/file/Valuing-Carers-2015.pdf

Catalani, C., & Minkler, M. (2010). Photovoice: A review of the literature in health and public health. *Health Education and Behaviour*, *37*(3), 424–451. https://doi.org/10.1177/1090198109342084

Corry, M., & While, A. (2009). The needs of carers of people with multiple sclerosis: A literature review. *Scandinavian Journal of Caring Sciences*, *23*, 569–588. https://doi.org/10.1111/j.1471-6712.2008.00645.x

Craig, P., Dieppe, P., Macintyre, S., Michie, S., Nazareth, I., & Petticrew, M. (2013). Developing and evaluating complex interventions: The new Medical Research Council guidance. *International Journal of Nursing Studies*, *50*(5), 587–592. https://doi.org/10.1016/j.ijnurstu.2012.09.010

Cummins, R. A. (1997). *The Comprehensive Quality of Life Scale (CoMQoL-A5) Manual*. Toorak, Vic.,: Deakin University.

Dayapoğlu, N., & Tan, M. (2017). The care burden and social support levels of caregivers of patients with multiple sclerosis. *Kontakt*, *19*(1), e17–e23. https://doi.org/10.1016/j.kontakt.2016.12.001

Department of Health [DoH]. (2014). *Care Act 2014: Factsheet 8 – Carers*. Retrieved from https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/366089/Factsheet_8_-_Carers.pdf

DesRosier, M. B., Catanzaro, M., & Piller, J. (1992). Living with chronic illness: Social support and the well spouse perspective. *Rehabilitation Nursing*, *17*(2), 87–91. https://doi.org/10.1002/j.2048-7940.1992.tb01519.x

du Plooy, D. R., & Pretorius, C. (2014). The caregiver experience: A South African perspective on caring for people with multiple sclerosis. *Journal of Psychology in Africa*, *24*(4), 361–369. https://doi.org/10.1080/14330237.2014.980623

Esch, T., & Stefano, G. B. (2005). The neurobiology of love. *Neuro Endocrinology Letters*, *26*, 175–192.

Faucher, M. A., & Garner, S. L. (2015). A method comparison of photovoice and content analysis: Research examining challenges and supports of family caregivers. *Applied Nursing Research*, *28*(4), 262–267. https://doi.org/10.1016/j.apnr.2015.02.005

Ferrans, C. E., Zerwic, J. J., Wilbur, J. E., & Larson, J. L. (2005). Conceptual model of health-related quality of life. *Journal of Nursing Scholarship*, *37*(4), 336–342. https://doi.org/10.1111/j.1547-5069.2005.00058.x

Fletcher, A. J. (2017). Applying critical realism in qualitative research: Methodology meets method. *International Journal of Social Research Methodology*, *20*(2), 181–194. https://doi.org/10.1080/13645579.2016.1144401

Frith, H., & Harcourt, D. (2007). Using photographs to capture women's experiences of chemotherapy: Reflecting on the method. *Qualitative Health Research*, *17*(10), 1340–1350. https://doi.org/10.1177/1049732307308949

Gafari, S., Khoshknab, M. F., Nourozi, K., & Mohamadi, E. (2017). Informal caregivers' experiences of caring of multiple sclerosis patients: A qualitative study. *Iranian Journal of Nursing and Midwifery Research*, *22*(3), 243–247. https://doi.org/10.4103/1735-9066.208168

Giordano, A., Cimino, V., Campanella, A., Morone, G., Fusco, A., Farinotti, M., . . . Solari, A. (2016). Low quality of life and psychological wellbeing contrast with moderate perceived burden in carers of people with severe multiple sclerosis. *Journal of the Neurological Sciences*, *366*, 139–145. https://doi.org/10.1016/j.jns.2016.05.016

Golla, H., Mammeas, S., Galushko, M., Pfaff, H., & Voltz, R. (2015). Unmet needs of caregivers of severely affected multiple sclerosis patients: A qualitative study. *Palliative and Supportive Care*, *13*(6), 1685–1693. https://doi.org/10.1017/S1478951515000607

Gottberg, K., Chruzander, C., Einarsson, U., Fredrikson, S., Johansson, S., & Widén Holmqvist, L. (2014). Health-related quality of life in partners of persons with MS: A longitudinal 10-year perspective. *British Medical Journal Open*, *4*(12), e006097. https://doi.org/10.1136/bmjopen-2014-006097

Haley, W. E., Levine, E. G., Brown, S. L., & Bartolucci, A. A. (1987). Stress, appraisal, coping, and social support as predictors of adaptational outcome among dementia caregivers. *Psychology and Aging*, *4*, 323–330. https://doi.org/10.1037/0882-7974.2.4.323

Harper, D. (2012). Choosing a qualitative research method. In D. Harper & A. R. Thompson (Eds.), *Qualitative research methods in mental health and psychotherapy* (pp. 83–97). Chicester, UK: Wiley-Blackwell.

Hayre, C. M., & Muller, D. J. (2019). *Enhancing healthcare and rehabilitation: The impact of qualitative research*. New York, NY: CRC Press.

Herzog, H. (2011). The impact of pets on human health and psychological well-being: Fact, Fiction, or Hypothesis? *Current Directions in Psychological Science*, *20*, 236–239. https://doi.org/10.1177/0963721411415220

Jo, S., Brazil, K., Lohfeld, L., & Willison, K. (2007). Caregiving at the end of life: Perspectives from spousal caregivers and care recipients. *Palliative and Supportive Care*, *5*(1), 11–17. https://doi.org/10.1017/S1478951507070034

Kaminska, O., & Foulsham, T. (2013). *Undestanding sources of social desirability bias in different modes: Evidence from eye-tracking*. Retrieved from https://www.iser.essex.ac.uk/research/publications/working-papers/iser/2013-04.pdf

Kanner, A. D., Coyne, J. C., Schaefer, C., & Lazarus, R. S. (1981). Comparison of two modes of stress measurement: Daily hassles and uplifts versus major life events. *Journal of Behavioral Medicine*, *4*(1), 1–39. https://doi.org/10.1007/bf00844845

Katsavos, S., Artemiadis, A. K., Zacharis, M., Argyrou, P., Theotoka, I., Chrysovitsanou, C., & Anagnostouli, M. (2017). Predicting caregiving status and caregivers' burden in multiple sclerosis. A Short Report. *Neurological Research*, *39*(1), 13–15. https://doi.org/10.1080/01616412.2016.1254942

Kinney, J. M., & Stephens, M. A. P. (1989). Hassles and uplifts of giving care to a family member with dementia. *Psychology and Aging*, *4*(4), 402–408. https://doi.org/10.1037/0882-7974.4.4.402

Labiano-Fontcuberta, A., Mitchell, A. J., Moreno-García, S., & Benito-León, J. (2014). Cognitive impairment in patients with multiple sclerosis predicts worse caregiver's health-related quality of life. *Multiple Sclerosis*, *20*(13), 1769–1779. https://doi.org/10.1177/1352458514532398

Landis, J. R., & Koch, G. G. (1977). The measurement of observer agreement for categorical data. *Biometrics*, *33*, 159–174. https://doi.org/10.2307/2529310

Lawton, M. P., Kleban, M. H., Moss, M., Rovine, M., & Glicksman, A. (1989). Measuring caregiving appraisal. *Journal of Gerontology: Psychological Sciences*, *44*(3), 61–71. https://doi.org/10.1093/geronj/44.3.P61

Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal and coping*. New York, NY: Springer.

Leung, D. Y., & Chung, B. P. M. (2019). Content analysis: Using critical realism to extend its utility. In P. Liamputtong (Ed.), *Handbook of research methods in health social sciences*. Singapore, Singapore: Springer.

Levitt, H. M., Bamberg, M., Creswell, J. W., Frost, D. M., Josselson, R., & Suárez-Orozco, C. (2018). Journal article reporting standards for qualitative primary, qualitative meta-analytic, and mixed methods research in psychology: The APA Publications and Communications Board task force report. *American Psychologist*, *73*(1), 26–46. https://doi.org/10.1037/amp0000151

Lorenz, L. S., & Kolb, B. (2009). Involving the public through participatory visual research methods. *Health Expectations*, *12*, 262–274. https://doi.org/10.1111/j.1369-7625.2009.00560.x

Maguire, R., & Maguire, P. (2020). Caregiver burden in multiple sclerosis: Recent trends and future directions. *Current Neurology and Neuroscience Reports*, *20*, 18. https://doi.org/10.1007/s11910-020-01043-5

Master, S. L., Eisenberger, N. I., Taylor, S. E., Naliboff, B. D., Shirinyan, D., & Lieberman, M. D. (2009). A picture's worth: Partner photographs reduce experimentally induced pain. *Psychological Science*, *20*(11), 1316–1318. https://doi.org/10.1111/j.1467-9280.2009.02444.x

Matsunaga, M., Yamauchi, T., Nogimori, T., Konagaya, T., & Ohira, H. (2008). Psychological and physiological responses accompanying positive emotions elicited on seeing favorite persons. *The Journal of Positive Psychology*, *3*, 192–201. https://doi.org/10.1080/17439760801999560

Maxwell, J. A. (2012). *A realist approach for qualitative research*. Thousand Oaks, CA: Sage.

McCabe, M. P., Ebacioni, K. J., Simmons, R., McDonald, E., & Melton, L. (2015). Unmet education, psychological and peer support needs of people with multiple sclerosis. *Journal of Psychosomatic Research*, *78*, 82–87. https://doi.org/10.1016/j.jpsychores.2014.05.010

McConnell, A. R., Brown, C. M., Shoda, T. M., Stayton, L. E., & Martin, C. E. (2011). Friends with benefits: On the positive consequences of pet ownership. *Journal of Personality and Social Psychology*, *101*, 1239–1252. https://doi.org/10.1037/a0024506

McCurry, M. K. (2013). An exploratory study of decision making by informal caregivers of individuals with multiple sclerosis. *Journal of Neuroscience Nursing*, *45*(1), 52–60. https://doi.org/10.1097/JNN.0b013e318275b252

Meca-Lallana, J., Mendibe, M., Hernández-Clares, R., Caminero, A. B., Mallada-Frechin, J., Dávila-Gonzalez, P., . . . Amigo-Jorrín Mdel, C. (2016). Predictors of burden and depression among caregivers of relapsing-remitting MS patients in Spain: MS Feeling study. *Neurodegenerative Disease Management*, *6*, 277–287. https://doi.org/10.2217/nmt-2016-0014

MS Trust. (2020). *Prevalence and incidence of multiple sclerosis*. Retrieved from https://www.mstrust.org.uk/a-z/prevalence-and-incidence-multiple-sclerosis

National Academies of Sciences Engineering and Medicine. (2016). *Families caring for an aging America*. Washington, DC: The National Academies Press.

O'Connor, C., & Joffe, H. (2020). Intercoder reliability in qualitative research: Debates and practical guidelines. *International Journal of Qualitative Methods*, *19*, 1–13. https://doi.org/10.1177/1609406919899220

Opara, J., & Brola, W. (2017). Quality of life and burden in caregivers of multiple sclerosis patients. *Physiotherapy and Health Activity*, *25*, 9–16. https://doi.org/10.1515/pha-2017-0002

Pakenham, K. I. (2001). Application of a stress and coping model to caregiving in multiple sclerosis. *Psychology, Health and Medicine*, *6*(1), 13–27. https://doi.org/10.1080/13548500125141

Peacock, J., Chur-Hansen, A., & Winefield, H. (2012). Mental health implications of human attachment to companion animals. *Journal of Clinical Psychology*, *68*(3), 292–303. https://doi.org/10.1002/jclp.20866

Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). Caregiving and the stress process: An overview of the concepts and their measures. *The Gerontologist*, *30*, 583–593. https://doi.org/10.1093/geront/30.5.583

Petrikis, P., Baldouma, A., Katsanos, A. H., Konitsiotis, S., & Giannopoulos, S. (2019). Quality of life and emotional strain in caregivers of patients with multiple sclerosis. *Journal of Clinical Neurology*, *15*(1), 77–83. https://doi.org/10.3988/jcn.2019.15.1.77

Rapley, M. (2003). *Quality of life research: A critical introduction*. London, UK: Sage.

Rivera-Navarro, J., Benito-Leon, J., Oreja-Guevara, C., Pardo, J., Dib, W. B., Orts, E., & Bello, M. (2009). Burden and health-related quality of life of Spanish caregivers of persons with multiple sclerosis. *Multiple Sclerosis*, *15*(11), 1347–1355. https://doi.org/10.1177/1352458509345917

Rollero, C. (2016). The experience of men caring for a partner with multiple sclerosis. *Journal of Nursing Scholarship*, *48*(5), 482–489. https://doi.org/10.1111/jnu.12231

Ruby, J. (1991). Speaking for, speaking about, speaking with, or speaking alongside — An anthropological and documentary dilemma. *Visual Anthropology Review*, *7*(2), 50–67. https://doi.org/10.1525/var.1991.7.2.50

Shaw, R. L., Bishop, F. L., Horwood, J., Chilcot, J., & Arden, M. A. (2019). Enhancing the quality and transparency of qualitative research methods in health psychology. *British Journal of Health Psychology*, *24*, 739–745. https://doi.org/10.1111/bjhp.12393

Stanley, I. H., Conwell, Y., Bowen, C., & van Orden, K. A. (2014). Pet ownership may attenuate loneliness among older adult primary care patients who live alone. *Aging and Mental Health*, *18* (3), 394–399. https://doi.org/10.1080/13607863.2013.837147

The WHOQOL Group. (1995). The World Health Organization quality of life assessment (WHOQOL): Position paper from the World Health Organization. *Social Science and Medicine*, *41*(10), 1403–1409. https://doi.org/10.1016/0277-9536(95)00112-K

Thompson, A., Kobelt, G., Berg, J., Capsa, D., Eriksson, J., & Miller, D. (2017). New insights into the burden and costs of multiple sclerosis in Europe: Results for the United Kingdom. *Multiple Sclerosis*, *23*(2_suppl), 204–216. https://doi.org/10.1177/1352458517708687

Todres, L., Galvin, K., & Dahlberg, K. (2006). Lifeworld-led healthcare: Revisiting a humanising philosophy that integrates emerging trends. *Medicine, Health Care and Philosophy*, *10*(1), 53. https://doi.org/10.1007/s11019-006-9012-8

Topcu, G. (2015). Using Photovoice in health psychology research: A methodological discussion. *Health Psychology Update*, *24*(2), 29–35.

Topcu, G., Buchanan, H., Aubeeluck, A., & Garip, G. (2016). Caregiving in multiple sclerosis and quality of life: A meta-synthesis of qualitative research. *Psychology & Health*, *31*(6), 693–710. https://doi.org/10.1080/08870446.2016.1139112

van der Hiele, K., van Gorp, D. A. M., Heerings, M. A. P., Jongen, P. J., van der Klink, J. J. L., Beenakker, E. A. C., . . . Visser, L. H. (2019). Caregiver strain among life partners of persons with mild disability due to relapsing-remitting multiple sclerosis. *Multiple Sclerosis and Related Disorders*, *31*, 5–11. https://doi.org/10.1016/j.msard.2019.03.005

Verbakel, E., Tamlagsrønning, S., Winstone, L., Fjær, E. L., & Eikemo, T. A. (2017). Informal care in Europe: findings from the European Social Survey (2014) special module on the social determinants of health. *European Journal of Public Health*, *27*(suppl_1), 90–95. https://doi.org/10.1093/eurpub/ckw229

Wang, C. C. (1999). Photovoice: A participatory action research strategy applied to women's health. *Journal of Women's Health*, *8*(2), 185–192. https://doi.org/10.1089/jwh.1999.8.185

Wang, C. C., & Burris, M. A. (1994). Empowerment through Photo Novella: Portraits of participation. *Health Education Quarterly*, *21*(2), 171–186. https://doi.org/10.1177/109019819402100204

Wang, C. C., & Burris, M. A. (1997). Photovoice: Concept, methodology, and use for participatory needs assessment. *Health Education and Behaviour*, *24*(3), 369–387. https://doi.org/10.1177/109019819702400309

Weber, R. P. (1990). *Basic content analysis* (2nd ed.). Newbury Park, CA: Sage.

Wilkinson, H. R., & Nair, R. D., (2013). The psychological impact of the unpredictability of multiple sclerosis: A qualitative literature meta-synthesis. *British Journal of Neuroscience Nursing*, *9*, 172–178. https://doi.org/10.12968/bjnn.2013.9.4.172

Williams, S., Sheffield, D., & Knibb, R. C. (2014). A snapshot of the lives of women with polycystic ovary syndrome: A photovoice investigation. *Journal of Health Psychology*, *21*(6), 1170–1182. https://doi.org/10.1177/1359105314547941

Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology & Health*, *15*(2), 215–228. https://doi.org/10.1080/08870440008400302

Yardley, L., Morrison, L., Bradbury, K., & Muller, I. (2015). The person-based approach to intervention development: Application to digital health-related behavior change interventions. *Journal of Medical Internet Research*, *17*(1), e30. https://doi.org/10.2196/jmir.4055

Supporting Information

The following supporting information may be found in the online edition of the article:

Appendix S1. Coding Template for Photovoice analysis.