ORIGINAL RESEARCH

Strategies for the relief of burden in advanced dementia care-giving

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Abstract

Aim. This paper is a report of a study conducted to uncover the strategies that women caregivers of relatives with advanced dementia use to rest from care-giving.
Background. Respite consists of activities and situations that briefly take caregivers away from their care-giving responsibilities. Qualitative studies are focusing on respite as an outcome and are deepening our knowledge about the experience of caregivers' rest. The strategies that caregivers use to relieve the burden, however, are not fully known.
Method. A qualitative approach was used influenced by the work of Charmaz's constructivist grounded theory. Twenty-three female primary caregivers of relatives with advanced dementia participated in semi-structured interviews between November 2006 and March 2009 in Spain. Data collection was guided by the emergent analysis and ceased when no more relevant variations in the categories were found.
Findings. Taking leave from the life of care-giving is the general strategy that caregivers use to rest from their caregivers selves. The key issue is to be able to connect with a different world from that of care-giving. Three strategies that participants use to leave the life of care-giving follow: (1) Connecting with one's own life, (2) building moments of life in common with the sick relative and (3) keeping in touch with care-giving.
Conclusion. To have respite from care-giving implies distancing oneself from the care-giving identity and reveals the caregiver's need for alternative selves to have *true* breaks from caring. Nurses are in a unique situation to foster respite as an inner experience.

Keywords: dementia, family care, grounded theory, informal care, nursing, qualitative research, respite care

Introduction

The rapid transition of care of elders from institutions to community is an option that most European countries have adopted; it combines support for individuals from families, the state and voluntary and private welfare organisations (Scharf & Wenger 1995). Spain is not different from this European trend. The family, the market and the state are, in

this order of importance, the three agencies that intervene in the provision of long term care with 78% of the older people population receiving help only from their families (Casado-Marin & López i Casasnovas 2001). Although formal care services have increased in recent years, important differences still exist across the country (Rogero-Garcia *et al.* 2008).

Women caregivers usually give the largest part of long term care, experience more care-giving costs than men do (Hirst 2004, Raschick & Ingersoll-Dayton 2004, Papastavrou *et al.* 2009) and are more likely to suffer disabilities (Puga-González & Abellán-García 2004). Despite this fact, 61·5% of women caregivers in Spain have declared never receiving any formal support (Yanguas-Lezaun *et al.* 2001). Caregivers contribute enormously to our society and yet are unsupported. The need for community health services more attuned with their needs has been voiced in the literature (Gil-Garcia *et al.* 2005, Bover-Bover & Gastaldo 2007).

Caregivers of persons with dementia experience high levels of burden (Papastavrou *et al.* 2007); they can present caregivers with extraordinary difficulties to manage (Brody 1990). They require permanent attention and caregiver presence to the extent that metaphorically it is said that the caregiver's day has 36 hours (Mace & Rabins 1997). This case is especially so in the final stages of disease as the sick person care takes up nearly all of a caregiver's time (Aguglia *et al.* 2004). Many of the caregivers' disorders develop because they do not take time for themselves (Jouzapavicius & Weber 2001). Caregivers are indeed in a unique position of giving and needing care themselves.

Background

Care-giving limits and constrains caregivers' lives (Twigg & Atkin 1994) and the losses that caregivers of people living with dementia experience has been voiced in the literature since early days (Farran *et al.* 1991). Of significance is the loss of self resulting from the constrictions of normal activities; here the being of the caregiver becomes engulfed by care-giving activities (Skaff & Pearlin 1992). The more encapsulated by care-giving one's life is, the more vulnerable it is to the loss of self; the more the caregiver must be vigilant and the more dependent the cared for person is, the less opportunities the caregiver will have to express fully the self (Skaff & Pearlin 1992). Hence, these caregivers and particularly women are more likely to experience loss of self. People develop the sense of self in joint interactions with others and the self concept helps a person anticipate their social role while accommodating to social action (Butt & Langdridge 2003). Caregivers of people with dementia have scarce opportunities to compensate for their losses of self and

at the same time are left with no resources for other social action but care-giving. Indeed, caring demands the adoption of a life style that isolates women caregivers from the outside world and the home becomes 'as a prison' (Graham 1983, p. 26).

Although socially isolated, caregivers develop a diversity of helpful strategies to cope with their care-giving situation (Ekwall *et al.* 2007, Cooper *et al.* 2008, Salin *et al.* 2009). They benefit most from problem solving and emotional cognitive strategies (Kuuppelomäki *et al.* 2004). Maintaining outside interests, keeping time for one's self and taking the mind off things are some of the strategies that caregivers find helpful in relieving the burden of care (Loukissa *et al.* 1999, Kuuppelomäki *et al.* 2004, MacDonald *et al.* 2006, Salin *et al.* 2009). Emotion- focused coping strategies seem to protect Alzheimer's caregivers from developing higher anxiety levels (Cooper *et al.* 2008). Recent evidence suggests that caregivers' ways of coping need to be recognized and that relevant assistance is crucial in helping caregivers to have a more acceptable and sustainable situation (Brunton *et al.* 2008).

Respite services are part of social policy intended to relief the burden of care and to support caregivers' coping strategies (Jeon *et al.* 2005, Lee & Cameron 2005, Arksey & Glendinnign 2007). Previous studies have pointed to the importance for caregivers to have private time and space (Ashworth & Baker 2000, Brown & Alligood 2004, Upton & Reed 2005), have highlighted that respite allows caregivers to re assume a sense of their original lives (Smyer & Chang 1999, Ashworth & Baker 2000). For caregivers, respite services offered them normality and freedom and enabled them to engage freely in a sort of normal life (Ashworth & Baker 2000). However, their effectiveness is unclear (Stoltz *et al.* 2004, Mason *et al.* 2007, Shaw *et al.* 2009) and gender inequality in their provision has been noticed (Twigg & Atkin 1994, Team *et al.* 2007). When responding to caregivers' respite needs, a simplistic engineering model of stress has been endorsed by health and social care professionals (Upton & Reed 2005). Thus it has been concluded that to implement effective service delivery, the experience of caregivers needs to be better understood (Upton & Reed 2005).

But respite must also be regarded as a result and not just as a service that can be delivered (Chappell *et al.* 2001). It can be an everyday experience for caregivers (Stoltz *et al.* 2006), consisting of activities and situations that briefly take caregivers away from their care-giving responsibilities; to highlight its temporal nature, it is suggested to consider respite as a break (Chappell *et al.* 2001). For caregivers, respite is intrinsically beneficial (Ashworth & Baker 2000); it

enables them to endure caring for their relatives (Piercey & Dunkley 2004) and to support them (Stoltz *et al.* 2006). From their points of view, mental breaks are essential for a real respite (Teitelman & Watts 2004).

Due to the research emphasis on the visible and instrumental aspects of care-giving, the need for qualitative research has been voiced (Nolan *et al.* 1996, 2003), particularly in the area of respite care (Shaw *et al.* 2009). Qualitative studies have set the stage for understanding respite as an inner experience (Smyer & Chang 1999, Chappell *et al.* 2001, Teitelman & Watts 2004, de la Cuesta-Benjumea 2009) and helped to distinguish it from respite as a service (Strang & Haughey 1998, 1999). How caregivers relieve the burden of care, however, remains to be fully described. Women caregivers are the most exposed to social isolation and to the burden of care. This situation justifies the attention given to them in this study.

The study

Aim

The present study aims at uncovering the strategies that women caregivers of relatives with advanced dementia use to rest from care-giving. It is part of a major study into care-giving relief in situations of vulnerability (de la Cuesta-Benjumea *et al.* 2006).

Design

A qualitative approach was used influenced by the work of Charmaz's constructivist grounded theory (Charmaz 2000, 2006) by sharing the assumptions about the constructed nature of data and categories, engaging in reflexivity and by seeking and representing participant's views and voices as integral to the analysis (Charmaz 2009). This study has been reported in detail elsewhere (de la Cuesta-Benjumea 2010).

Participants

Participants were female primary caregivers of relatives with advanced dementia recruited with the help of health professionals in primary healthcare centres in Alicante and Elche (Spain). Of the 24 women invited to participate, 23 were interviewed. Sampling was sequential. A purposeful sampling strategy (Morse 1989) was initially employed seeking to select long-time caregivers of relatives with advanced dementia who were completely dependent. As analysis proceeded, the emergence of variations was favoured through theoretical

sampling this emergence resulted in a sample detailed in Table 1.

Data collection

Altogether, 23 semi-structured interviews and one group session to validate findings were conducted, between November 2006 and March 2009. Interviews lasted 40–90 minutes, were audio-taped and transcribed verbatim. The format of the interviews was that of a conversation with a structure and a purpose (Kvale 1996). In nine instances the cared for person was present as the caregiver had to look after him/her. The validating sessions took place in a health centre with eight participants and lasted 90 minutes. Field notes were taken and were included in the findings. In line with grounded theory procedures, data collection proceeded concurrently with analysis and ended when theoretical saturation was achieved (Strauss & Corbin 1998). Thus, data were collected in four waves; the last one consisted of the validating session and a final interview, conducted after an extended period of analysis with the purpose to

Table 1 Participant characteristics

	N = 23
Age	
< 40	1
40–50	4
51–60	12
61–70	3
> 70	3
Education	
No studies	3
Primary	11
Secondary	4
Vocational	3
University	2
Residence with sick relative	
Co-reside	15
No reside	8
Kinship	
Daughters	16
Daughters in law	2
Wives	4
Niece	1
Care-giving situation	
Solo	17
On a rota basis	6
Caring for two relatives at the same time	4
Time care-giving (years)	
1–5	14
6–11	7
> 12	2

validate and saturate the categories relating to burden relief strategies.

Ethical considerations

Permission to conduct the study was obtained from the University research ethics committee and the management board of the healthcare areas involved.

Data analysis

Grounded theory analysis involves open, axial and selective coding, the elaboration of memos and diagrams (Strauss & Corbin 1998). Constant comparison analysis took place after data were entered into QSR Nvivo (QSR International, Southport, UK). As analysis developed, theoretical sampling took place to seek for variations in the emerging category (Charmaz 2000) Codes pertaining to the strategy of *being another person* first emerged. They were developed, refined, sorted and collapsed to become categories and some codes were renamed. Open coding continued to elicit further categories, *joint life and connected with care* emerged. Data were examined to account for variations and further data were collected and analysed to complete sub categories. By comparing them, the category *taking leave from the life of caregiving* emerged as the core category that represents participants' experience and accounts for the strategies that they used to relieve the burden of care.

During analysis, relevant publications were consulted and analytic memos were developed (Strauss 1987, Strauss & Corbin 1998). Writing memos helped the conceptualization of data and guided theoretical sampling. Diagrams were used to visualize links between categories (Strauss 1987, Strauss & Corbin 1998). Along the process, reflexive notes were produced recognizing the subjective and constructed nature of the analysis (Charmaz 2009).

Rigour

The study complies with the canons of grounded theory (Strauss & Corbin 1998, Charmaz 2006). As categories emerged, they were saturated and validated against data and participants individually and, lastly in the group session. Through this process of validation, participants had the opportunity to clarify, contest or support the analysis. Categories were supported and enriched by the additional comments made by participants. In order to maximize the trustworthiness of findings, they were also discussed with a group of professional providers with expertise in the care of people with dementia.

Findings

Other findings of the study had been reported referring to the experience of rest (de la Cuesta-Benjumea 2009) and to the conditions that give caregivers' rest legitimacy (de la Cuesta-Benjumea 2010). This paper increases the understanding about how women caregivers relieve the burden of care.

For caregivers, to rest does not convey to be idle, on the contrary, caregivers rest by doing, by thinking and relating to others but in different ways than those linked to care-giving. For example, one participant said what it feels like *be another person*:

As a matter of fact I go out, I speak and I am other!. No speaking about my parents, but about whatever, I am other, sincerely I am another person!

The study showed that taking a leave from the life of caregiving is the overall strategy that caregivers use to rest from their caregiver selves. The strategies that caregivers use to leave their care-giving lives follow.

Taking leave from the life of care-giving

For participants to rest involves more than changing places and scenarios. The essential is to occupy other selves, to 'disconnect' from being a caregiver as some said during the interviews. Thus, having physical, social and symbolic spaces, in which to become someone different is of crucial importance.

Taking leave from the life of care-giving does not imply existing in a social void, the key for a true rest is to connect with a different world from that of care-giving. However, caregivers do not always fully achieve it. The study showed that caregivers leave their care-giving life by: (1) Connecting with one's own life, (2) building moments of life in common with the sick relative and (3) keeping in touch with care-giving.

Connecting with one's own life

Caregivers connect with a life of their own via three means: (1) performing, taking on other identities, (2) 'Evadirse' (mentally escaping) and (3) isolating themselves.

During the interviews participants usually said that they 'do something else' and that they 'entertain' themselves as a way of achieving rest. They list a variety of activities they reported were great, some of those were the ones they lost and now intend to connect with them. Thus, they related that they rested when they went to the beach to have breakfast with their husband, when they did the things that they always liked to do, or when they cleaned, ironed, or tidied up their

homes. Other activities included when they go out to the shops or to do errands, when they look after their grand-children, when talking on the phone with a daughter or when they had friends coming to their places for leisure such as playing cards with them. A close examination of the data shows that when caregivers' act upon other identities such as being a grandmother, a wife, a mother, or a friend, they attain rest. Thus, it is of little relevance what the caregiver actually does or where she is, but it is fundamental who she is in her relations to others and the social space that she occupies. A caregiver gave an example:

…when I went to the Faculty I disconnected, because I had to attend classes or when not, I met with friends to comment 'I miss this and that', then I disconnected there.

The caregiver in the quote above shows that her social identity is given by others and that having a student self enables her to be disconnected from her caregiver self. To exit from the life of care-giving and rest is hence conditioned by the opportunity of having an alternative life to that of caregiver of a sick relative. This finding conveys the need for physical, social or symbolic spaces, in which caregivers could become someone different. To stay at home, for instance, all afternoon with not much to do and no one to speak to it is not for caregivers a way of achieving rest as there are no possibilities of engaging themselves in other identities and the hours close to their relative could become long and heavy as participants said. By the same token, going out with no purpose or no one to be with, is not truly a break from care-giving as a caregiver conveys:

But on other occasions, I go out and see myself alone and I say to myself 'what a life, this, what kind of life is this?'. The work at home and all the things I manage and then go out for a short walk and I am by myself.

'Evadirse' (mentally escaping) is the second way caregivers have to rest and is grounded in participants' own words. The term is accurate as they escape from the care-giving situation with their minds. In a symbolic manner, they exit the life of care-giving; during these moments they are not conscious of their caregiver selves. For instance, a participant said that when she watches TV her head 'does not function for something else' and another said that she does not stop doing things 'to avoid thinking'. These escapes allow caregivers to connect with other lives whether they are fictitious like a TV programme or real as in the case of a woman caregiver who returns with her mind to the years she lived in France and collects fruit. The life she had is now an imaginary place to go for a rest without leaving her responsibility of care-giving and getting around practical restrictions.

Isolating from the care situation is the third means that permits caregivers to exit their life of care-giving. It implies withdrawing to a private place where they can be on their own. During the interviews they related that they went to a room, closed the door and isolated themselves from whatever happened outside that door, or went to the laundry room, to have a smoke or to the kitchen to be 'separated by a wall'. Also by studying or reading they could isolate themselves:

…when she is sleeping…I read and during this hour and during this hour or hour and half that I am reading I am like in a bubble, I isolate from everything.

In this way, participants make breaks in the process of care-giving; they retire to private places where they can distance from their caregivers' selves. These are spaces and situations where they can stay alone. This need is expressed when participants said that what they like most is to be alone and on their own meaning with this their need to isolate from the care-giving demands.

Building moments of life in common
In spite of the cognitive deterioration of the cared for person, participants build spaces of life in common with their sick relative where both can rest. It can be said that the cared for person can rest from the disease and the caregiver from her care-giving life. This life in common is built by sharing moments of leisure and rest and by getting the sick relative to have a rest.

Caregivers share moments of leisure with their sick relatives, by watching TV together, by speaking of past events or family affair, by going out for a short walk or errands or even going together on holidays. This life in common with the cared for person is illustrated by a participant:

So, here (in the sitting room with her sick relative) I entertain myself on a swing and if not, watching TV. I go and I say 'mother, shall I put the TV on? I turn her and sit her up and she looks at the TV and I stay there with her for a while 'look at Pantoja (a singer) poor her! What they are doing to her!' and I talk with her, I talk a lot with her.

Caregivers also take the chance of sleeping while their sick relatives are resting and some even laid on the same bed sharing in this way their relative rest:

…I came to the point of lying in bed with her in the afternoon, I mean during the siesta time. I thought 'I did not sleep much tonight, she is now quiet, I am going to lie with her'.

To make the cared for person rest is the second mechanism that permits caregivers to have moments of life in common with their sick relatives. Thus, for instance, caregivers make

their relatives relax by putting their favourite programmes on the TV, playing music, by touching them or by creating whatever environment that keeps them calm. A caregiver describes how, by addressing her aunt's old self, she calmed her down:

… She has always been very coquette, she liked that we put on make up, that we painted her lips and combed her hair, and this calmed her down a lot. When we could sit her up we said to her, 'We have to make you pretty'. We did that, made her pretty, combed her hair once and over again, painted her lips once and over again.

In the same way, participants did all they could to gather people visiting the cared for person, thus, as one caregiver said, 'he was seeing a different life', that is, a different life from that of sickness and care-giving, a life that enabled him for a short time to be other person.

Keeping in touch with care-giving
Lastly, caregivers physically get out of their places to have a rest but remain connected to their sick relatives or to the care-giving world. These are outings, in which caregivers keep in touch with their caregivers' selves.

Participants related that when they go out they carry their sick relative in their heads or minds. Thus, although they are in other places and doing different things, they keep close to their relatives wondering if they are OK without them, following with the mind the care-giving schedule, making frequent phone calls to see how the cared for person is and being watchful for anything that their relative could need. This situation is common to all the participants in the study and is epitomized by the mobile phone. All of them had one that as an invisible thread connected them with care-giving. They never left their homes without it and remained watchful in case they received a message. A participant spoke about it:

…This week I went to a wedding (laugh).

P: And how was it, could you relax?

R: Well, not much, I always have the thought, aghh! Thinking always the same!.

P: On what?

R: If they are going to call me, as many times I went out shopping and in the middle that is! I got a call, 'mom the granny this, granny that'

P: So you go out with the mobile phone R: Yes, with the mobile, loaded!.

In a different way, there are participants that go out and keep their connection with the world of care-giving by visiting other sick relatives or by participating in activities related to their caregiver's self such as caregiver's workshops or support groups. A caregiver illustrates this:

Well, a neighbour of mine that also takes care of her father in law and her own mother, we went together to this short course. We went together there, I motivated her and said to her: 'come on, lets get lost for a day', I said 'and we are going to get lost for the whole day, even if it is for speaking the same, but we also find relief by speaking, talking to other people that are as we are' do we not?.

While participants reported advantages derived from these outings such as changing the scenario or 'getting some air', they also said that in many of these situations they could not properly rest or that it was an 'inverted commas' rest. Further, they gave examples showing that these outings could add to the burden of care due to the worry and stress of thinking what could happen to the care for persons in their absence. Not surprisingly, caregivers sometimes settled for the lesser of two evils and opted for not leaving the care-giving scenario.

To be someone different does not require to be physically absent from the care-giving scenario, nor does the physical absence guarantee it as it has just been shown. To go out connected with care-giving is a very common situation in participants' experiences and illustrates their difficulty in connecting with an alternative life to that of care-giving. Indeed, the success of taking a leave from the life of care-giving depends on the possibilities and opportunities that caregivers have to leave behind their caregivers' selves.

Discussion

Study limitations

The present study has limitations. Sharing a household radically affects the experience of caring and it is important in the construction of caring relationships (Twigg & Atkin 1994, Read 2000). Most of the caregivers drawn for this study co-resided with their dependents; this fact might have influenced the importance they gave to going out connected to care-giving. It is also possible that this sample, mainly but not entirely drawn from a socially deprived group of carers had limited the results of the present study. Other groups of dementia carers with more social and economic resources could well have additional ways of finding respite. Given that in Spain, neither social care nor formal support for caregivers are well developed, the alternatives that participants had to find respite opportunities are indeed limited. In other scenarios, with more social support, the variety of respite strategies could be greater. During the interviews extensive probing was required as it was not easy for participants to

What is already known about this topic

- Caring demands the adoption of a life style that isolates women caregivers from the outside world.
- Although socially isolated, caregivers develop a diversity of helpful strategies to cope with their care-giving situation.
- Respite can be an everyday experience for caregivers; it consists of activities and situations that briefly take caregivers away from their care-giving responsibilities.

What this paper adds

- Taking leave from the life of care-giving is the general strategy that caregivers use to rest from their caregivers selves.
- To have respite implies distancing from the care-giving identity, hence caregivers do need to have alternative selves to have *true* breaks from caring.
- Partial breaks are common in caregivers' experience, they might be seen as real breaks, while in caregivers' experience, they are not and even could add to their burden.

Implications for practice and/or policy

- New types of interventions that foster caregivers' leisure activities, promote their engagement in different social roles and that encourage the means of having a family life with the sick relative should be considered.
- Nurses must give advice and support for caregivers to retain as much as they can of a life of their own.
- Nurses should recognize caregivers' strategies to achieve relief and support them and discourage those that, disguised as breaks from caring, add stress.

speak of ways of achieving rest while they were concerned for the health of their dependent. Problems in terms of the depth of disclosure may occur where the care recipient is present (Lane *et al.* 2003). In this study, this problem occurred during some interviews and could also pose a limitation to the data collected.

Discussion of findings

Family care is more than activities and signifies a relationship (Twigg & Atkin 1994, Carter 2001), it demands both identity and labour (Graham 1983). To have respite from care-giving implies distancing oneself from an identity as the

present study has shown. It revealed caregivers' needs for alternative selves to have *true* breaks from caring. When caregivers do different things and sustain different relationships, other that those relating to caring for the sick relative, they can become someone else and thus, rest from being a carer. People create their biographies and identities not in a vacuum but in a continual interaction with others (Butt & Langdridge 2003, Blaxter 2004). These findings are consistent with previous studies and give a concept that unifies disperse information relating to caregivers' activities and sources of respite (Ashworth & Baker 2000, Chappell *et al.* 2001, Teitelman & Watts 2004, Upton & Reed 2005, Stoltz *et al.* 2006). They also increase understanding of caregivers' activities and difficulties in achieving respite. It is not just to have private time, interests outside their care-giving situation and get away from care-giving roles (Ashworth & Baker 2000, Brown & Alligood 2004, Upton & Reed 2005, Furlong & Wuest 2008), as the present study has shown, caregivers also need alternative selves even if that implies to do some work, to carry on with duties other than care-giving.

The current study helps to further understand the importance of caregivers having a sense of their original lives with respite (Smyer & Chang 1999, Ashworth & Baker 2000) and has contributed to the operationalization of the concept of mental break (Chappell *et al.* 2001, Teitelman & Watts 2004). It also supports the argument that burden relief interventions should recognize that it is essential for caregivers to have 'a life outside caring' (Lundh & Nolan 2003, p. 110). Further, as the maintenance of emotional bonds is vital in enabling carers to cope with their situation (Carter 2001), the strategy of constructing moments of life in common with the sick relative contributes to keeping alive these bonds and enables caregivers to distance from their care-giving role. The self is forged through the process of socialization, pragmatism says, here the individual presents a socially viable self taking the vantage point of others (Butt & Langdridge 2003). If there is no one to interact with, however, the making of a new self would be very unlikely.

While other studies make references to breaks that are total, real or complete (Chappell *et al.* 2001, Teitelman & Watts 2004) and it is acknowledged that there is a 'quintessential meaning of respite' for caregivers (Strang & Haughey 1998, p. 237), much remains unsaid about partial, unreal or incomplete breaks. Twigg and Atkin (1994) in their seminal research found that time away from the cared for person 'was never fully their time' (p. 38) and a recent study showed that a large proportion of the caregivers were only partially or not very satisfied with how they spent their time to get respite (Lund *et al.* 2009). Caregivers in fact do achieve partial

breaks as this study has shown; these types of breaks are very common in participants' experiences. They do deserve major attention from healthcare professionals and community nurses in particular as they might be seen as real breaks, while in caregivers' experience, they are not and even could add to their stress. The core category of taking leave from the life of care-giving deepens our understanding of caregivers' experience of relief and shows that is has grades, something that has passed unnoticed in the literature. This study thus adds to the literature on respite care drawing attention to the importance of connecting with other selves for the relief of burden.

It has been suggested that health professionals engage caregivers as partners in the intervention process of burden relief, to mediate these interventions from being obstructive to facilitative of relief (Nolan *et al.* 1996). Uncovering the different strategies that caregivers use to achieve relief contributes to the development of a partnership model.

Conclusion

The knowledge produced by this study not only contributes to nurses' critical reflection on the way they view respite, but it also gives them the means to promote it. To recognize caregivers' strategies to achieve relief would enable nurses to support them and discourage those that, disguised as breaks from caring, add stress. The relief of the burden of care goes beyond removing caregivers from their homes. Nurses must engage in new types of interventions that foster caregivers' leisure activities, they should promote their engagement in different social roles and encourage the means of having a family life with the sick relative.

Nurses are well positioned to help families to draw a viable plan for living with a long-term illness and give advice and support for caregivers to retain as much as they can of a life of their own. Also, in the chronic phase, when family members are pulled towards mutual dependency and care-giving, nurses could assist in the crucial task of maintaining maximal autonomy and in this way favouring the conditions for caregivers achieving real breaks from care-giving. Indeed, nurses are in a unique position to help caregivers to achieve a more acceptable and sustainable care-giving situation; they have contact with caregivers over time and could asses their needs and acknowledge their strengths and foster respite as an inner experience.

Finally, further research is needed with a more diverse sample to include male caregivers, caregivers from different countries and socioeconomic background and with caregivers who do not co-reside with their relative and those who care for relatives with different chronic conditions.

Conflict of interest

No conflict of interest has been declared by the author.

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