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Exploring dimensions of social support and resilience when providing care at the end of life: a qualitative study

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ABSTRACT

Background: Research shows that formal and informal social support can facilitate resilience in carers. There is a paucity of research exploring social support and resilience amongst recently bereaved informal carers.

Aim: To examine how the presence or absence of distinct dimensions of social support facilitate or hinder resilience in recently bereaved informal carers.

Participants: 44 bereaved carers, who had been identified by GP as 'main carer' of someone recently deceased (3–12 months), aged between 38 and 87 years old (mean= 67).

Methods: Thematic analysis then the Ecological Framework of Resilience as an organisational tool to develop overarching themes in the data. We used the Sherbourne and Stewart model to identify social support that was lacking as well as social support that was present.

Results: A range of social support types were identified. There was an emphasis on the importance of relationships with both health professionals and family members, including the care recipient. However, social support was not necessary for resilience if the participant had other resources.

Conclusions: Social support for carers providing end of life care is almost exclusively based around end of life care 'work'. In comparison to other research our study suggests that relationships with family and health professionals are paramount. Multidimensional support is needed for carers to enhance their resilience.

Introduction

The end of life is increasingly associated with comorbid conditions, frailty and smaller family units to provide support (Seale, 2000) alongside the increase in life expectancy (Public Health England, 2016). For many people, the last few months of life see the most intensive contact with health and social services, and transfers between care settings are frequent (Hanratty et al., 2012). It is often the informal carers bear responsibility of navigating this system (Stoltz, Uden, & Willman, 2004; Lowson et al., 2013). Nearly 1.4 million people aged 65 and over provide unpaid care for a partner, family or others but only 77,635 (in 2012–2013 in England) receive any carer specific support services (NHS Information Centre, 2013). Recent research explores the contributions of family caregivers at the end of life in terms of hours of care and expenditure (Rowland, Hanratty, Pilling, van den Berg, & Grande, 2017). Almost two thirds of older carers have a long-term health problem or disability themselves (Carers UK, 2014). Carers frequently report (68.8%) that their role has an adverse effect on their mental health (The Princess Royal Trust for Carers, 2011).

Caring is a stressful life event. Carers must adapt to and manage social, physical and emotional challenges. The Ecological Framework of Resilience (Windle & Bennett, 2011) based on the Ecological Systems Theory (Bronfenbrenner & Ceci, 1994) explores how people live in and interact in their environments. It reflects how resilience operates across multiple levels, which in turn interact with each other. Resilience is defined as:

> The process of effectively negotiating, adapting to, or managing significant sources of stress or trauma. Assets and resources within the individual, their life and environment facilitate this capacity for adaptation and 'bouncing back' in the face of adversity. (Windle, 2011; p. 163)

Multiple criteria have been used to classify people as resilient or not, most notably widowers, which removes the reliance on proxy measures and identifies resilient individuals and the characteristics that contribute to resilience (Bennett, 2010; Moore & Stratton, 2003). Bennett's (2010) operationalisation of resilience has been used to classify other carers, including older spousal dementia carers (Soulsby & Bennett, 2015). Their criteria included; 1. There must be a significant challenge (caregiving), 2. No sign of (di)stress, 3. Maintaining a life of meaning and satisfaction (a sign of bouncing back), 4. Actively participating in life (a sign of managing), 5. Current life seen as positive (a sign of adaptation).

There is growing interest in resilience of people who care for someone at the end of life (Monroe & Oliviere, 2007; Grande et al., 2009). Recent literature contributes to knowledge of resilience during end of life care (MacArtney et al., 2015), the factors that contribute to, and hinder resilience (Donnellan, Bennett, & Soulsby, 2015) and which carers of family members at the end of life need more support from health services (McNamara & Rosenwax, 2010). Informal carers perform a crucial role in maintaining and

supporting care recipients and consequently have support needs themselves (Moens, Higginson, & Harding, 2014). Some carers report not wanting to provide such care again (Currow et al., 2011).

One factor that may be crucial in sustaining carers providing end of life care is social support, a 'community-level' factor in the Ecological Framework of Resilience (Windle & Bennett, 2011). International research suggests married people are able to die at home more frequently that those who are divorced, widowed or unmarried, highlighting the importance of family carer and social support (Gao et al., 2013; Cohen, Pivodic, & Miccinesi, 2015). Soulsby and Bennett (2015) defined social support as being "a transactional process whereby our relationships provide a platform for the exchange of emotional and practical support" (p.110); a concept fundamental to the experience of carers and patients negotiating health services, settings and professionals. Research shows that informal support is associated with high baseline resilience and lower levels of institutionalisation over time for people with dementia (Gaugler, Kane, & Newcomer, 2007).

Sherbourne and Stewart (1991) identified five distinct dimensions of social support related to people who are chronically ill: emotional support (positive affect, empathic understanding, attachment); affectionate (expression of love); informational (advice, guidance, feedback); tangible (practical assistance); and positive social interaction (availability of others to do fun things together). Exploring the different dimensions of social support (Sherbourne & Stewart, 1991) has been previously reported: how social support mediates the relationship between being optimistic and caregiver quality of life (Brand, Barry, & Gallagher, 2016), to explore psychological resilience (Isaacs et al., 2017) and to explore mental wellbeing and resilience (Khawaja, Ibrahim, & Schweitzer, 2017).

Using similar terms to Sherbourne and Stewart (1991), other research has reported that emotional support has been found to predict cognitive functioning better than physical support (Ellwardt, Aarsten, Deeg, & Steverink, 2013) and affectionate support and positive social interaction to reduce psychological burden in dementia carers (Han et al., 2014). Sherbourne and Stewart (1991) dimensions have been used as framework for identifying social support in research on spousal dementia carers (Donnellan, Bennett, & Soulsby, 2016), but not been used to explore end of life caregiving. To our knowledge the Sherbourne and Stewart (1991) model has not been utilised to explore the experiences of carers providing end of life care.

There is a paucity of research exploring social support and resilience amongst recently bereaved carers. This paper explores the experiences of people who cared for a family member at the end of life. We examine the dimensions of social support that recently bereaved carers used to facilitate or hinder resilience when providing end of life care.

Method

Participant selection

This study focuses on a subsample of 44 bereaved carers from a wider study of 120 bereaved carers (Hanratty et al., 2012). The wider study (Hanratty et al., 2012) explored the experience of carers who had cared for someone at the end of life and who experienced more than one transition from one care setting to another; e.g. from home into a nursing home or hospice, or from hospital to home and to nursing care. A qualitative approach was appropriate due to the lack of exploration and understanding of the experience of moving from one place of care to another. The participants were chosen for further analysis as previous analysis showed that had they had spoken at length about support whilst providing care at the end of life and spontaneously mentioned areas of social support that facilitated or hindered resilience. Recruitment was purposeful via opting in to the study team via reply slip after contact from their GP via the Primary Care Research Network or from the GP directly. It was not possible to track who did not opt in, and none of the participants once interviewed withdrew.

Setting

This study draws from 20 women and 24 men interviewed, of which 19 were spousal carers, 20 were offspring carers, and 4 were classified as 'other' (1= friend, 1= granddaughter, 1 = brother in law, 1 = brother). The age of the carers ranged between 38 and 87 years old (mean= 67). Most participants (31/44) had previously lived with the person they had been caring for. The care recipient died from a range of illnesses, including: heart failure (11); Stroke (13); COPD (8); Lung cancer (5); breast cancer (1); and colorectal cancer (5). Care recipients were aged between 74 and 97 (mean 85.7 years old). The usual place of care varied with most participants (n = 32) living at home. Other places of care included nursing homes (4), residential or sheltered accommodation (4), hospice (1), hospital (1), and family members homes (2). The socio-economic status distribution of the participants (based on postcode data) was broadly representative of similar demographics in the British population (ONS, 2011).

Data collection

Semi structured interviews were conducted face-to-face between 2010 and 2011 and digitally recorded at the bereaved carers' homes. Interviews lasted between 60 minutes and 2 hours 45 minutes, and a topic guide was developed by the study team, and used by LR to illicit exploration of the experience of caring in different settings and the experience of the carer providing care. The support received in terms of social, family and health professional support was also explored and there were also questions about how information was provided to the carer and who provided information. Interviews were conducted until data saturation.

Data analysis method

Participants in this sample had been classified as resilient using the Bennett (2010) operationalised method of classifying resilience. The components of the classification of resilience include; there must be a significant challenge: caregiving, no sign of (di)stress, maintaining a life of meaning and satisfaction (a sign of bouncing back), actively participating in life (a sign of managing), and current life seen

as positive (a sign of adaptation). Twelve of the participants were classified as not resilient and 32 participants were classified as resilient based on the Bennett (2010) using data from interviews.

We used a thematic approach as an exploratory method to read and code the full cohort of interviews (LR, BH). Social support was a key theme in the preliminary analysis. The lead author re-coded the transcripts looking at the emerging description of social support and supportive relationships described by the carer during their end of life caring responsibilities.

The remaining analysis then departed from the principles of thematic analysis. We used the Ecological Framework of Resilience (Windle & Bennett, 2011) as an organisational tool to develop overarching themes in the data. The Framework method was used to organise preliminary data and for detailed analysis of social support the software QSR NVivo10 was used to organise the data. We used the Sherbourne and Stewart (1991) model to identify social support that was lacking as well as social support that was present.

Results

The results are mapped onto the themes of the ecological framework of resilience, to explore the presence or absence of resources from individual (including the support taken from immediate caregiving relationship), community and society perspectives and to examine how these resources map together with the social support model (Sherbourne & Stewart, 1991). Throughout the results section terms in [] refer to the dimensions of social support from the Sherbourne and Stewart (1991) model and some examples highlight the presence of support and others the absence of support.

Individual assets

Drawing on the support of the deceased care recipient

Participant 7 shows elements of individual/psychological assets facilitating resilience; he refers to the 'continuity' of the patient in 'accepting dying' and draws on his own identity 'I am hoping I can be the same'. He also stays positive throughout the interview, captured here with 'life carries on". This participant has many features that appear to facilitate his resilience; he accepts the situation he is in, and he is positive when reflecting on the caring experience.

> … she knew she was dying and she accepted it … and I am hoping I can be the same [emotional]. I don't know, once someone tells you, you are going to die, it's difficult I can't, I can't comprehend what it might mean to me, I am hoping I would go the same way, accept it, it's part of life [emotional], it just ends and life carries on. (Participant 7, Brother in Law, Resilient).

Participants benefited from the support of the person they were caring for, in particular the emotional support provided and the ability of the care recipient to navigate the system together.

Carer resilience is facilitated by this unique relationship between the carer and care recipient, particularly when adapting to and managing the stress of coping with bereavement. This participant shows insight and dimensions of emotional support when describing how his sister-in-law knew she was dying and how she accepted it. Elements of social support work together throughout this participants' transcript to facilitate the resilience he has during and after the death.

Material resources were also important, for both participants who were resilient and those who were not. Material resources facilitated the end of life care 'work' in some cases as well as the resilience of the participants. Those who had the ability to organise and pay for aids such as wheelchairs, stools and bathing equipment and enough money to pay for transport in difficult situations reported more positively on their care experience as well as had less distress about the caregiving experience. The flexibility of the participant's workplaces, childcare considerations and the carer's access to aftercare (such as bereavement counselling) was more widely reported in participants who were classified as resilient. Participant 31, who was classified as not resilient, reported material resources she accessed and this was important to her in the absence of other types of support,

> I have got a carer, I have got a care plan they come in the morning, one comes in the morning, one comes in the evening [tangible] (Participant 31, wife of deceased, not resilient).

Community resources

Carers wanting more support than they received from family

In general, carers reported needing more support from family than they received particularly emotional and tangible support as well as the wider family recognising their difficulties. The presence of emotional and tangible support facilitated resilience. Carers with little familial support were more likely to be not resilient. The next quote illustrates that caring for a person at the end of life can be emotionally and physically draining.

> … you think oh well they get in touch kind of thing, and you just don't realise time goes by and you are bloody knackered [lack of emotional support], I am tired out, my mother wasn't an easy person [lack of emotional support] … so emotionally I was completely drained as well as physically from going there, or just going there at lunchtime [lack of tangible support] … so you are too tired and knackered to kind of think straight really that's the big issue and they should be thinking for you [lack of emotional, informational and tangible support]. (Participant 27, offspring carer of parent with stroke, Resilient)

Throughout the data, bereaved carers reported needing a multidimensional supportive network to facilitate resilience. In the example above, the participant describes how her husband was supporting her in caring for her mother but she still felt she needed wider support. An ecological perspective of resilience works well to explain how these dimensions are interlinked. For example, participants discuss many forms of support that they would have liked when providing end of life care for example and emotional and informational support would have been welcomed. Material resources or practical assistance were sometimes lacking from the participant's community assets and participants said they much needed, along with the support of the community including family, friends and neighbours.

Some resilient carers described having little or no familial support, implying that resilience is not exclusively centred on social support. Participant 30 described how she did not have the support necessary to undertake such a consuming role, but did have the insight and negotiation skills to manage the situation she was in and to protect herself from potential stress. The interplay here between the dimensions of social support and the way the carer deals with the resources they have is important to whether they are classified as being resilient or not. The participant explained:

(my mother) said I don't want to (go into hospital)… her pleading with me, with her eyes", the participant "wasn't brave enough to do 24 hour care on my own [emotional, information and tangible support lacking] …and I know that I couldn't cope with that mentally [emotional and informational support lacking], emotionally I knew I couldn't cope with that.

The reason the carer gave for not wanting to care for her mother '24 hours' was,

I knew basically it would be all down to me, and then of course there was, my dad was still demanding to be visited every day [lack of tangible and positive social interaction] (Participant 30, Offspring carer of parent with heart failure, resilient)

This participant draws on her psychological assets to facilitate her resilience. She negotiates, manages and adapts to the stressful situation by opting out of the 24-hour care she reports she was implicitly expected to do, thus showing her resilience in the face of adversity. Here, the adversity was not providing care for someone at the end of the life, but providing care without the resources she felt she would need to successfully carry out this caring role. She lacked community support to carry out further caring duties, but had the insight to identify what she lacked and to take appropriate action.

Participants were also aware of the insecure nature of the caring; they may have been navigating the role at one point, but had awareness that one unexpected problem could have caused their fragile situation to become unmanageable:

I said to him, which I feel very guilty about… on the day he died actually, that if I became ill or anything else that I wasn't too sure… how we were going to manage… because he needed… help undressing and getting into bed [tangible support lacking] …there was a lot of work, and it was, we were getting, I was getting rather tired [tangible and emotional support lacking], so, so we were getting to a point where probably we needed help. (Participant 29, Offspring carer of parent with heart failure, resilient).

There were plenty of examples of the tangible care, offered to carers by other family members and which was well received.

[friend present] and her husband took me every day didn't you, except one weekend when Monica and Jeff took me didn't they. Because I can't drive [tangible support present] (Participant 28, spousal carer of stroke patient, resilient).

Societal resources

Multidimensional support from health professionals facilitates informal carer role

Many participants spoke at length of the time and patience the health professionals had for the care recipient and spoke in encouraging terms about the care received. The emotional, tangible and informational support offered by health professionals that was gladly received by carers was also frequently mentioned. In both excerpts below, the participants had been classified as resilient and a positive relationship with health care professionals did give the impression that it facilitated resilience in participants.

The doctors when you were there, you know would ask you, you know if you had got any questions, do you want to know anything about this [informational, tangible], this, and this, and they were very good [emotional] 100% involved you (Participant 44, Offspring care of parent with breast cancer, resilient)

Well every time I went in you know the doctors or the nurses would come up and put me in the picture [informational] as to what was actually happening. They were very good, very good, and they were very nice to me as well [affectionate], very courteous you know and sympathetic [emotional] you know (Participant 26, spousal carer of stroke patient, resilient)

Not all participants reported positive support from health professionals and sometimes participants felt obstructed by the interventions of health professionals. Participant 43 describes a move to a hospice and how knowledge about the condition and prognosis was not forthcoming by the health care staff;

if anybody would have talked to us about that, then we might have been more, we would have been more prepared [lack of emotional, informational and tangible support], but there was never any mention anywhere, that death might overtake all plans that we had got. So that really was dreadful, that she had to die in the corner of a ward, behind a curtain [lack of tangible]. I asked twice for a private ward, but they couldn't find one. (Participant 43, spousal carer of person with colorectal cancer, not resilient)

Perceived lack of support from professionals hindered resilience and compounded difficulties in adapting to the caring role. A lack of informational support such as knowledge from professionals about how to access services or miscommunication about prognosis sometimes caused negative consequences for the carers. Participant 43 reports how he lacks reassurance, someone to help him navigate the health care system and a lack of support in deciding upon end of life care and place of care/death. His lack of support contributed to him feeling regret about the way his wife died:

…it was basically my fault… I didn't understand the situation because nobody had said you do realise this might not work [lack of informational support] …if only somebody had said, you do realise it can go like that then I would have got her home, and she would have been with her friends, they would have been here with her, visiting and the last day she didn't know much but she would have been here and loved it [positive social interaction] (Participant 43, spousal carer of person with colorectal cancer, not resilient)

Support that prioritises the system not the carers

Many of the interviews conveyed a sense that the care system was imposing processes on carers without any recognition of, or flexibility to the individuals' needs or wishes. It was sometimes unclear whether the problem lay with interdisciplinary communication, or if the 'system' was used by professionals as an excuse to cover inability or unwillingness to act. The participants discussed the health and social care system working against them, rather than for the

benefit of the families, suited more towards the process and bureaucracy;

> there were capacity laws that had just come through and social workers hadn't had training on it, so we were stuck for 9 months because they hadn't had training on it. (Participant 27, offspring carer of parent with stroke, resilient)

Discussion

The Princess Royal Trust for Carers (2011) reported that a caring role frequently has adverse effects on carer's mental health. Informal carers perform a crucial role in maintaining and support care recipients (Moens et al., 2014) and exploring factors that contribute to or hinder resilience is an area of growing interest. Our aim was to explore how the presence or absence of distinct dimensions of social support (Sherbourne & Stewart, 1991) could facilitate or hinder resilience for carers providing end of life care and to see how these dimensions mapped with the Ecological Framework of Resilience (Windle & Bennett, 2011). We focused on social support as recent research suggests it is associated with high baseline resilience and lower levels of institutionalisation over time, particularly pertinent in this sample of participants with experience of providing informal care in multiple settings at the end of life. We explored how participants' social support influenced their resilience in this situation, whilst they were caring for their loved ones. Analysis of the interview data using the subcategories within the Sherbourne and Stewart (1991) model explored the multidimensional nature of social support and were mapped onto the ecological model of resilience. The emotional, informational and tangible support provided by both family and health professionals were fundamental to facilitating resilience for carers providing informal care at the end of life (Rose, 1999).

Individual assets are important in this data, particularly how participants drew on the relationship and support of the deceased care recipient as well as other more obvious networks such as family and health care professionals. This supportive relationship facilitated resilience, in particular the emotional and tangible support offered from the deceased care recipient, and the way this increased positivity and acceptance of bereavement and death. Poor relationships with family members or health professionals did not prohibit a carer showing many resilient qualities, but poor support did seem to make life harder for the carers and they needed to draw on psychological assets more explicitly and use any material resources they had effectively to soften the loss of these relationships (Soothill et al., 2001).

Carers in this sample generally wanted more support than they received from family and the data were mixed with regard to the support received from health care professionals. The discrepancies between carer's perceptions of social support and actual social support are important. Distinct dimensions of social support did contribute towards bereaved carers being classified as resilient or not, but the relationship between social support and resilience was not linear. Some participants were classified as resilient without having a supportive family providing all the support the person perceived they needed, and some participants were classified as resilient without good working relationships with the health professionals involved in the end of life care 'work'. But, *enough* support was needed by the bereaved carer to be able to fulfil their caring role successfully and to feel, on reflection, they had adapted and managed well. These dimensions of support did not need to be provided by support networks at the same time but needed to be provided by the most appropriate person. The quality of the social support the participants sought was almost exclusively based around their end of life 'work'. They sought emotional support from family and professionals around them, informational support to guide their knowledge and understanding of the situation or the trajectory of illness or dying, and tangible support to help make their caring role easier; for the patient, themselves and their families.

Carers and health professionals have complex relationships which have been well reported elsewhere (Ward-Griffin & McKeever, 2000; Kirk, 2008; Murray, Boyd, Sheikh, Thomas, & Higginson, 2004; Bauer, Fitzgerald, Haesler, & Manfrin, 2009). In this study we explored how multidimensional support from health professionals facilitates informal carer roles and in contrast, how the perceived lack of support from professionals hindered resilience and compounded difficulties in adapting to the caring role. The provision of a seamless service, one shaped around the needs of patients, carers and families is a core principle of the UK National Health Service (Department of Health, 2010) but this was not always the experience of the participants in this study. Participants conveyed the sense that the care system was imposing processes on carers without any recognition of the participants' needs or wishes (McPherson, Kayes, Moloczij, & Cummins, 2014).

This study has many strengths: we have explored the experience of bereaved carers shortly after their bereavement, a difficult to reach group, who were identified by GPs as being a key carer in an older person's life. This point in time is often difficult to explore and relies on participants reflecting on their experiences with accuracy. Carers cared for close family members (typically spousal or offspring carers) and the care recipient was terminally ill with one or more of a range of illnesses. Carers also had experience of providing informal care in at least two places of care, so they typically had a number of experiences to draw on. They spoke at great length about their experience of caring for someone at the end of life. The carers were broadly representative of the UK population in terms of socio-economic status. Our methodology brings other strengths to this study; the in-depth nature of the interviews allowed carers to discuss their experiences of the last few months, weeks and days of the cared for persons life. The analysis of the data supports two models previously cited in the literature; the ecological framework of resilience (Windle & Bennett, 2011) and secondly, the Sherbourne and Stewart model (1991) exploring dimensions of social support.

There are limitations to our study; Qualitative research rules out causality and directionality between social support and resilience cannot be assumed. We did not explicitly ask about factors that facilitated or hindered resilience from the perspective of the carers. However, this could be considered a strength as the carers were asked about

support and spontaneously discussed the themes above (Becker, 1996). Our total sample of carers in the wider study was 120, but we focused on a subsample of 44 who in previous analysis had spoken about social support. The other participants in the sample may have something to add to this exploration in terms of why they did not access social support available to them or whether they did not feel they had social support. They also may have contributed to whether their access to or use of social support hindered or facilitated their resilience. Recruitment of carers for this study was exclusively through GP surgeries with support from the primary care research network. Previous research has reported that friendships are key supportive relationships for carers facing difficult challenges (Donnellan et al., 2016) and in this data, friends were almost completely missing as a group mentioned in the data. GP lists are more likely to contain family member carers than other carer relationships, although this does not explain why family carers only drew on the support of other family members.

We propose an additional two major subthemes in the facilitation of resilience in carers at the end of life: the relationships of the health professionals with the carers; and the families' relationships with each other. When exploring social support in a bereaved carer sample, we suggest at least one of the Sherbourne and Stewart model (1991) is not applicable to the experience of carers at the end of life (positive social interaction). We also propose that the Sherbourne and Stewart (1991) model can be used to describe how dimensions of social support are lacking and that this lack of social support dimensions compromises the carers' ability to negotiate, manage and adapt to significant sources of stress or trauma.

To conclude, our findings suggest that multidimensional support is needed for people who provide informal care for older people at the end of life. Social support that facilitates emotional wellbeing and understanding (emotional), increases advice, guidance and feedback (informational), and provides practical, timely support (tangible) is important to people providing informal care at the end of life. Social support is not crucial for informal carers to be resilient at this time. However, *enough* support is needed by carers to successfully negotiate, manage and adapt to the end of life caring 'work'/role. If social support is not evident, carers seem to draw strength from individual resources (psychological assets, staying positive, material resources) *if they have them*. Along with drawing on other community and societal resources they may still 'bounce back' and adapt in the face of this stressful event but it seems more difficult to do so without this valuable support. Literature suggests some carers who have previously provided end of life informal care would not do so again (Currow et al., 2011) and it is therefore essential that we explore ways to facilitate informal carers in adapting and bouncing back from the adversity of caregiving.

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