# Exploring dimensions of social support and resilience when providing care at the end of life

## Abstract

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

Methods: Thematic analysis of data from 44 in-depth interviews with bereaved carers exploring their experience of end of life transitions (from one place of care to another) for their deceased relative or friend.

Results: A range of social support types were identified. Key themes included: carers drawing on emotional and information support from the care recipient; carers requiring more emotional and tangible support; a need for multidimensional support from health professionals to facilitate their role as carers; and finally, how the carers feel the priority for professionals is often adherence to process rather the provision of support for carers. There was also an emphasis on the importance of relationships with both health professionals and family members.

Conclusions: Social support for carers providing end of life care is almost exclusively based around end of life care ‘work’. In comparison to other recent research suggesting friends are key in providing social support (Donnellan, Bennett & Soulsby, 2015), our study suggests that relationships with family and health professionals are paramount. Multidimensional support is needed for carers to enhance their resilience.

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## Introduction

As average age at death has risen (Public Health England, 2016) the end of life is increasingly associated with comorbid conditions, frailty, and smaller family units to provide support (Seale, 2000). 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 who bear the responsibility of navigating this system (Stolz, et al. 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). 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 (Brofenbrenner, 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. Windle (2011) defined resilience 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”.

Multiple criteria are often used to classify people as resilient or not (most notably widowers), removing the reliance on proxy measures and identified resilient individuals and the characteristics that contribute to this outcome (Bennett, 2010; Moore & Stratton, 2003). This operationalisation of resilience has been used to classify other carers, including older spousal dementia carers (Donnellan, Soulsby & Bennett, 2015). Their criteria included; 1. View their current life positively, 2. Currently actively participating in life, 3. Return to a life that had meaning and satisfaction, 4. Coping with no sign of distress.

There is growing interest in resilience of those who care for someone at the end of life (Oliviere & Monroe, 2008; Grande et al., 2009), in building on resilience during end of life care (MacArtney et al., 2015), the factors that contribute to, and hinder resilience (Donnellan et al., 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 patients and as a consequence have support needs themselves (Harding & Higginson, 2014).

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). 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”; a concept fundamental to the experience of carers and patients negotiating health services, settings and professionals. Sherborne 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). To our knowledge the Sherbourne and Stewart (1991) model has not been used to explore the experiences of carers providing end of life care.

Research shows that informal support is associated with high baseline resilience and lower levels of institutionalisation over time for people with dementia (Gaugler et al., 2007). Using similar terms to Sherbourne & Stewart (1991), other research has reported that emotional support has been found to predict cognitive functioning better than physical support (Ellwardt, Aarsten, Deeg, Steverick & 2013) and affectionate support and positive social interaction to reduce psychological burden in dementia carers (Han et al., 2014).

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

### Participants

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 explored the experience of carers who had cared for someone at the end of life and who had 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 (NIHR SDO 08/1809/2320). 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.

### The Interview

Semi structured interviews were conducted face-to-face between 2010-2011 and digitally recorded at the bereaved carers’ homes. Interviews were conducted by the lead author and one other researcher. Interviews lasted between 60 minutes and 2 hours 45 minutes, and in part explored the experience of caring in different settings and the experience of the carer providing care. The support they 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.

### Method of analysis

We used a thematic approach as an exploratory method to read and code the interviews. 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 as we sought to understand better the experiences of bereaved carers and determine which dimensions of social support contributed to resilience using the ecological framework as an organisational tool to develop overarching themes in the data (Windle & Bennett, 2011). The Framework method was used to organise preliminary data and for more detailed analysis of social support the software NVivo was used to organise the data.

The themes supported the model of Sherbourne and Stewart (1991). These supportive relationships included family relationships, health professional relationships and whether the carers felt, on reflection, that more support was needed from other people in helping them cope with caring for their loved one at the end of life.

We used the Sherbourne and Stewart (1991) model to identify social support that was lacking as well as social support that was present.

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| Table 1: Bennett (2010) operationalising resilience  |
| i. There must be a significant challenge: caregiving. |
| ii. No sign of (di)stress. |
| iii. Maintaining a life of meaning and satisfaction (a sign of bouncing back). |
| iv. Actively participating in life (a sign of managing). |
| v. Current life seen as positive (a sign of adaptation). |

Participants in this sample had been classified as resilient using the Bennett (2010) operationalised method of classifying resilience (Table 1).

## Results

20 women and 24 men were 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 socio-economic status distribution of the participants (based on postcode data) was broadly representative of similar demographics in the British population (ONS, 2011).

Family members and professionals were seen as supportive by carers. The deceased care recipient, other family members and health professionals were seen as providing the dimensions of social support which were most beneficial to the carer at this time.

Carers reported that some of the dimensions of support (emotional, informational, positive social interaction, tangible and affectionate; Sherbourne & Stewart, 1991) were present or absent at different times during the caring trajectory. Participants described many times where support was needed but not forthcoming.

The results are organised in line with the ecological framework of resilience to explore the presence or absence of resources from individual, community and society perspectives and to examine how these resources map together with the social support model (Sherbourne & Stewart, 1991).

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| **Participant ID number**  | **Carer relationship**  | **Age of carer** | **Age of patient** | **Health condition of patient** | **Is the carer resilient?**  | **Place of usual care for the patient** |
| 1 | Off spring | 59 | 92 | Heart Failure | Not resilient | With offspring  |
| 2 | Off Spring | 53 | 90 | COPD | Not resilient | Home alone |
| 3 | Off Spring | 61 | 89 | Stroke | Resilient | Multiple home |
| 4 | Off Spring | 64 | 89 | Heart Failure | Resilient | Home |
| 5 | Off Spring | 60 | 87 | Colorectal Cancer | Resilient | Home |
| 6 | Spousal | 83 | 83 | Stroke | Resilient | Home |
| 7 | Brother in Law | 68 | 80 | Heart Failure | Resilient | Home |
| 8 | Spousal | 74 | 75 | Lung Cancer | Not resilient | Multiple but home |
| 9 | Spousal | 76 | 78 | Stroke | Resilient | Home |
| 10 | Spousal | 66 | 70 | Lung Cancer | Resilient | Home |
| 11 | Spousal | 76 | 76 | Colorectal Cancer | Not resilient | Hospice |
| 12 | Spousal | 76 | 84 | COPD | Resilient | Home |
| 13 | Spousal | 79 | 76 | Stroke | Not resilient | Home |
| 14 | Spousal | 79 | 77 | COPD | Not resilient | Home |
| 15 | Spousal | 77 | 71 | Heart Failure | Not resilient | Home |
| 16 | Spousal | 77 | 78 | Stroke | Resilient | home |
| 17 | Brother | 84 | 81 | Lung Cancer | Not resilient | Brothers home |
| 18 | Off Spring | 63 | 84 | Stroke | Resilient | Sheltered |
| 19 | Off Spring | 53 | 86 | Heart Failure | Resilient | Sheltered |
| 20 | Off Spring | 62 | 89 | Heart Failure | Resilient | Residential |
| 21 | Off Spring | 63 | 90 | Stroke | Resilient | Nursing Home |
| 22 | Off Spring | 57 | 91 | Stroke | Resilient | Nursing home |
| 23 | Off Spring | 64 | 91 | Stroke | Resilient | Home |
| 24 (all men to here)  | Off Spring | 70 | 96 | Lung Cancer | Resilient | Residential |
| 25 | Off spring | 64 | 90 | Heart failure |  | Nursing home |
| 26 | Spousal | 70 | 89 | COPD | Resilient | Hospital  |
| 27 | Off spring | 49 | 87 | Stroke | Resilient | Care home |
| 28 | Spousal | 84 | 87 | Stroke | Resilient | Home |
| 29 | Off spring | 58 | 84 | Heart failure | Resilient | Home |
| 30 | Off spring | 62 | 84 | Heart failure | Resilient | Home |
| 31 | Spousal | 78 | 78 | Colorectal cancer | Not resilient | Home |
| 32 | Spousal | 59 | 72 | Heart failure | ` | Home |
| 33 | Spousal |  |  |  |  | Home |
| 34 | Off spring | 68 | 97 | Stroke |  | Home |
| 35 | Grandchild | 45 | 96 | COPD |  | Home |
| 36 | Off spring | 60 | 88 | Lung cancer |  | Home |
| 37 | Off spring | 60 | 87 | Heart failure |  | Home  |
| 38 | Spousal | 74 | 85 | Heart failure |  | Home |
| 39 | Niece | 65 | 85 | Heart failure |  | Home |
| 40 | Spousal | 82 | 82 | Colorectal cancer |  | Home |
| 41 | Spousal | 81 | 80 | Heart failure |  | Home |
| 42 | Off spring  | 50 | 78 | COPD |  | Home |
| 43 | Spousal | 75 | 75 | Colorectal cancer | Not resilient | Home |
| 44 | Off spring | 38 | 74 | Breast cancer | Resilient | Home  |

### 1. Presence of individual resources to facilitate resilience

### Drawing on the support of the deceased care recipient

Participants benefited from the support of the person they were caring for, particularly their emotional support and the ability of them to navigate the system together and be a source of knowledge. The participant below talks about how the care recipient ‘accepted’ she was dying and how he hoped he would think about death in the same way when his time came:

*“…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 [informational].” (Participant 007, Brother in Law, Resilient)*

Carer resilience can be facilitated by this unique relationship between the carer and care recipient, particularly when adapting to and managing the stress of coping with bereavement. The dimensions of social support here fit well with the Sherbourne and Stewart’s model (1991). This carer shows insight and dimensions of emotional support when describing how his sister-in-law knew she was dying and how she accepted it; he drew strength from the care recipient having information about the trajectory of the illness and in accepting this; informational support when the carers touches on how he understood the likely trajectory of dying; and informational support when he talks about how life carries on and will carry on for him after her death. These elements of social support work together in this example and throughout this carer’s transcript to facilitate the resilience he has during and after the death.

Participant 007 shows elements of 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 factors which appear to facilitate his resilience; he accepts the situation he is in, and he is positive when reflecting on the caring experience.

Another participant describes how she was co-dependent on her deceased husband and with his death she lost some of her positive social interaction and tangible support; but the participant was able to reflect and appreciate this support; her circumstances changed but she did value the situation she was in and reflected positively:

 *“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].*

*LR: There wasn’t anybody extra for your husband?*

*“No, no because he was virtually my carer, and my taxi and everything [tangible, emotional] because I had to stop driving.” (Participant 031, wife of deceased, not resilient)*

### 2. Absence of community resources threatening resilience

### 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. The presence of emotional and tangible support facilitated resilience. A lack of familial support appeared to increase the likelihood of the carers being classified as not resilient. Caring for a person at the end of life can be emotionally and physically draining as this next quote from a carer describes. Some carers focused on how they wanted the wider family to recognise their difficulties and provide some emotional and tangible support and also help with ‘thinking *for* you’;

*“…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 report needing a multidimensional supportive network to facilitate resilience. Some participants are classified as resilient and they may have some support in place, yet report needing further family and ‘outsider’ support. In the example above, the participant goes on to describe 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 further explain how these dimensions are interlinked. For example, participants discuss many forms of support which they would have liked when providing end of life care; psychological assets may be depleted and emotional and informational support welcomed, material resources or practical assistance may be lacking and much needed, as would 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 based 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*”.

Part of the reason that 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 [tangible and positive social interaction lacking]*” (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 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 (family relationships, family support, wider social 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 an 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. Or would have needed help” (Participant 29, Offspring carer of parent with heart failure, resilient).*

There were plenty of examples of the tangible care which was frequently offered to carers by other family members and 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).*

Throughout these interviews, carers would have welcomed more emotional and tangible support than was offered by family and friends.

### 3. Presence of societal resources facilitating resilience

### Multidimensional support from health professionals facilitates informal carer role

Carers and health professionals have complex relationships which have been well reported elsewhere (Ward-Griffin & McKeever, 2000; Kirk, 2001; Murray et al., 2004; Bauer et al., 2009). Many participants spoke at length of the time and patience the health professionals had for the person who was terminally ill and spoke in encouraging terms about the care received. The emotional, tangible and informational support offered by health professionals which was usually gladly received by carers was also frequently mentioned. Participants described how when they had chance to see the doctor or nurse in charge they were given useful and helpful information and also that the health professionals were often kind to the carers. In both excerpts below, the participants were 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 carers reported positive support from health professionals and sometimes carers felt obstructed by the interventions of health professionals. In the quote below the carer 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 considerable consequences for the carers. The carer reports a lack of someone to reassure him, a lack of support in knowing how to navigate the system, 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)*

Providing care for someone at the end of life involves continually adapting and managing changing illness trajectories and sometimes health professional personnel, places of care and negotiating other complex systems. Lack of support from health professionals potentially contributes to carers having less chance to negotiate or adapt to the stressful event in a positive way as they struggle with managing situations they are unfamiliar with. When participants have no other resources to draw on, such as a presence of individual, community or social resources to facilitate resilience, then a lack of support can be critical, hindering their resilience and the process of adapting and managing in stressful situation.

### Support that prioritises the system not the carers

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): this was not always the experience of the participants in this study. 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. 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)

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.

## Discussion

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 explored how participants’ social support influenced their resilience in this situation, whilst they were caring for their loved ones. Analysis of the interview data found that the subcategories within the social support overarching theme did map to the Sherbourne and Stewart (1991) model exploring the multidimensional nature of social support. 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. We also propose that the 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.

Fundamental to negotiating, managing and adapting to providing care at the end of life was the emotional, informational and tangible support provided by both family and health professionals. However there are caveats to this; these dimensions of support did not need to be provided by family members and health professionals at the same time but needed to be provided by the most appropriate person.

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.

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. 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.

This study has many strengths: we have explored the experience of bereaved carers shortly after their bereavement, who were identified by GPs as being a key carer in an older person’s life. Carers cared for close family members (typically spousal or parental 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. This point in time is often difficult to explore and relies on participants reflecting on their experiences with accuracy. The analysis of the data supports two models previously cited in the literature; the ecological framework of resilience (Windle & Bennett, 2011) and the interplay between factors which facilitate or hinder resilience (Windle, 2011) and secondly, the Sherbourne and Stewart model (1991) exploring dimensions of social support. We also add two dimensions of social support we feel are key to support carers at the end of life; positive health professional and family relationships and 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).

There are limitations to our study; first, we did not explicitly ask about factors which 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 and whether or not that 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, Soulsby & Bennett, 2015) 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.

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 needed by those 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.

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