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Providing help, support and care from a distance: summary of findings from an exploratory study of 'distance carers' in the UK



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Background to the study

Caring has been the focus of much research and has highlighted the valuable contribution of carers, as well as the challenges they may experience, in respect of finances; employment; physical and emotional health; social lives (Yeandle et al., 2007; King and Pickard, 2013; Macmillan Cancer Support, 2016). A group which has been relatively little studied in the UK are carers who provide care 'at a distance' from those they support (Koerin and Harrigan, 2002; Cagle and Munn, 2012; Edwards, 2014). However, this may represent a significant group, both in respect of the numbers of 'distance carers' and the amount of care and support they provide (Cagle and Munn, 2012). To date, most of the research in respect of distance caring has been conducted in the US, primarily in relation to older adults/people with dementia; although some research was also taking place in Germany at the same time as our study, suggesting that there is growing awareness of, and interest in, distance carers. Distance carers may undertake a range of caring roles, including the provision of direct care, emotional support, support around the house, and with finances and medication, arranging and monitoring formal care (Koerin and Harrigan, 2002; Milligan and Wiles, 2010; Metlife, 2004; Edwards, 2014). Distance carers may be the sole carer or provide help, care and support as part of a network (for example, providing care alongside other family members, friends or neighbours, or with paid carers also providing support) (Metlife, 2004). The evidence to date without of the UK has indicated a range of potential challenges for those caring from a distance. These include assessing the wellbeing of the person from afar, costs of travel/staying in touch, the impact on the amount of free time and time spent with other family members, changed working patterns and feeling left out of decisions (Koerin and Harrigan, 2002; Metlife, 2004). Further, some distance carers have identified rewards in respect of their caring roles (Koerin and Harrigan, 2002; Edwards, 2014).

There are a number of reasons why people may be caring from a distance. These include:

- Contemporary patterns of family life
- Family dispersal, due to family members moving away for education or employment
- A lack of local, suitable care provision has meant that some people have been moved 'out of area' to provide them with the support they have been identified as needing, but placing them at a distance from their support network.

As a consequence, many people may find themselves caring for a relative or friend from a distance. This study sought to address what appears to be an imbalance between the numbers of people providing help, support and care from a distance in the UK, and awareness of the experiences of this group. The study set out to:

- Explore the experiences of distance carers across the UK, using survey methodology
- Identify the roles and activities carried out by distance carers
- Identify the specific challenges, dilemmas and rewards which may be experienced by such carers, as well as the things that support them in their caring roles
- Develop further research questions based on the findings of this exploratory study.

Please note, distance carers may provide support to people in many different relationships, including relatives and friends. For simplicity, in this report we refer to people receiving care and support as 'relatives' or 'family members', while, however, recognising the multiplicity of caring relationships.

Study Methods

Ethical approval for the study was given in March 2017 by the Faculty of Health Sciences Research Ethics Committee at the University of Hull.

A volunteer sample was invited to participate in the study and the following inclusion/exclusion criteria were applied. People were invited to participate in the research if:

- They were aged 18 or over
- They were providing help, care and support for an adult friend or relative who lived at a distance from them which involved a minimum travel time of 1 hour, or they had provided such support in the previous 2 years
- The respondent and the person they provided help, care or support for both lived in the UK.

This was an exploratory study, therefore we did not seek to make a formal definition of the term 'carer' (for example, some studies have defined the types of tasks undertaken by carers, or the number of hours spent caring), as we wanted to be as inclusive as possible. Therefore, participants self-defined as 'providing help, care and support from a distance'. Much of the existing research on distance caring has focused on people caring for ageing parents. We recognised that carers may also be caring for people with learning, physical or sensory disabilities, mental health needs, long term health conditions, as well as needs associated with age and ageing. All such carers were included in the research. Further, we recognised that carers do not cease to provide care and support if and when their relative moves into a care/nursing home. Therefore we invited people to take part in the research if their relative lived in their own home or in a care or nursing home, or in-patient unit.

We defined distance in terms of the time taken to travel when visiting (as a minimum of one hour each way), rather than miles travelled. This recognises that different modes of transport require and permit different travel times. We considered a travel time of one or more hours to be a distance which could lead to specific challenges for carers; this also puts our study in-line with some previous research (for example, Thompsell and Lovestone, 2002; Metlife, 2004; Roff et al, 2007).

The study used an online survey (hosted by Bristol Online Survey - BOS) to conduct the research. This approach enabled the participation of carers from across all parts of the UK, ensured that a range of different carer voices could be heard, and ensured that participants could respond at their convenience (Chiasson et al., 2006; Graffigna and Bosio, 2006; Tates et al., 2009; Zwaanswijk and van Dulmen, 2014; Horrell et al., 2015).

A hard copy version of the questionnaire was available for participants who did not have internet access or preferred not to use it. The survey was initially developed by the research team, based on the available international literature. The draft survey was then checked with a small number of distance carers. The questionnaire included open ended/free response questions, as well as 'tick box' questions, generating qualitative data supported by descriptive quantitative data.

Recruitment to the study was undertaken via existing carer support agencies; through social media (using the Twitter page @dist_care); and community resources. A study flyer was

circulated via newsletters, placed on websites and noticeboards and shared via Twitter with key organisations. The survey was open from April to November 2017.

Overall 139 people completed the survey; 128 were included in the analysis.

Overview of people who completed the survey

- 89% were female
- 89% were White British
- The age range of participants was 21-75 years
- 67% were in employment (full or part time) or education or training
- Some carers reported that they help, support or care for more than one person
- Some carers also reported that they had their own health problems/disabilities
- The time carers reported that they spent caring per week ranged from 30 minutes – 50 hours.

Overview of the people they help, support or care for

- 62% were female
- 91% were White British
- Their age range was 18-95 years
- Their place of residence included own homes (66.5%); care homes (12.5%); NHS inpatient units (1.6%)
- 92% received help from others (such as other family members, paid carers) in addition to the distance carer.

Those receiving support included people who had dementia/memory loss (18.8%), learning disabilities (7.3%), mental health needs (7.3%), physical disabilities (16%), long term health conditions/illness (17.7%), sensory disabilities (9%), as well as older people (20.5%).

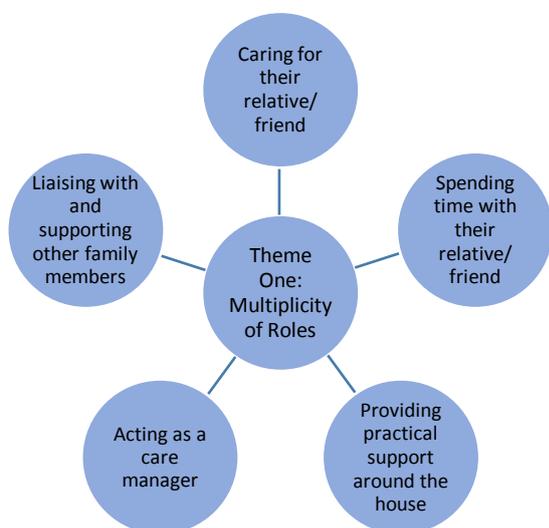
The distances travelled by carers are outlined below:

Distance	Number	Percentage of the sample
1-2 hours	52	40.6
2-3 hours	25	19.5
3-4 hours	17	13.3
4-5 hours	16	12.5
5+ hours	15	11.7
10+ hours	3	2.3

Key issues identified by participants

From the information shared by participants we identified five important issues. For each issue identified we provide an explanation of some of the main points raised, alongside individual participant quotes. Permission was sought for the use of all such quotes.

1. Distance carers carry out a multiplicity of roles



Carrying out a multiplicity of roles

Distance carers were carrying out a wide range of roles. Some (such as personal care) required them to be with the person. Others (such as acting as a care manager) could be carried out when they were together or apart from the person they supported.

“Spending time with her, assessing her needs, taking her out, buying clothes, personal items etc. Making sure staff know someone is watching out for her.”

2. Distance carers experience three key challenges



Challenges arising from distance

You can't just pop in

It can be hard for carers to know how the person is and how they are managing, when they are not able to see them and their environment:

“It's just a bit frustrating at times knowing that if I was living nearby then both our lives would be easier. I cannot offer hands on help and some situations need intervention in the early stages but by the time I hear of incidents it's a case of trying to put right something that shouldn't have happened in the first place.”

“In an emergency takes 5+ hours to get there.”

Bridging the distance gap

Carers need to travel and make regular phone calls, to keep in touch with the person they support. As a result of distance their visits could be lengthy, intense and infrequent, rather than 'little and often':

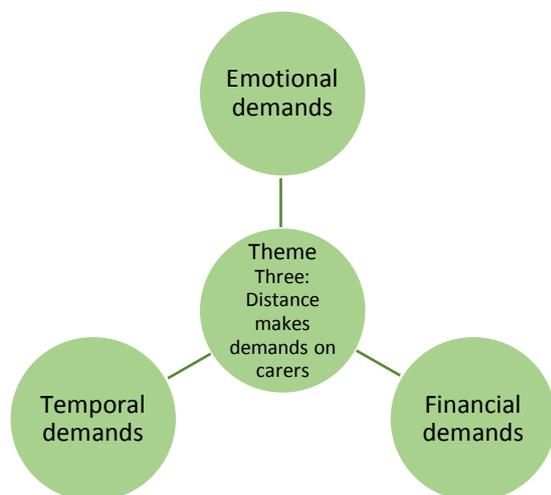
“Main difficulty is in frequency of visits. Would rather do little and often so can make bigger more consistent impact rather than come in like a whirlwind and try to do everything fast.”

Location, location, location

There are challenges which relate to living in a different geographic area to the person cared for. However, services do not always recognise and meet the needs of distance carers:

“We are largely hidden. Government & local authority initiatives generally assume that carers live in same local authority as person cared for, if not in same property. No joined up thinking/services. We are left to our own devices.”

3. Distance makes demands on carers



Distance makes demands on carers

Emotional demands

Carers report emotional concerns, such as worry and guilt, when caring at a distance:

"I worry about the situation all the time. It's like a background hum in my life. I worry when she's upset when I leave, I feel guilty but know that if I don't look after myself as well it will be counter-productive."

Financial demands

The expenses associated with providing support at a distance can take a toll - for example, petrol money, lost wages from taking time off work:

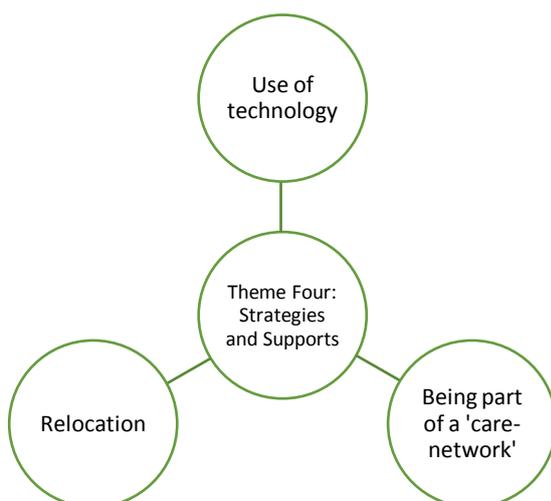
"I have recently reduced my hours at work to 32 hours per week to enable me to have a day off per week and fit in visits easier."

Temporal (time) demands

Providing support at a distance can be time consuming, taking carers away from other care roles, such as childcare. For this group of carers the need to travel added to the time required for caring:

"Dilemma... time for and commitments to my kids; versus driving down to help."

4. There are strategies and supports which may help distance carers



Strategies and supports

Use of technology

Using technology, such as Skype, mobile phones, or online shopping, can support care at a distance. Technology was helpful to some carers, but it is not useful in all circumstances:

"My parents' dementia has now prevented them from using any communication device more complicated than the landline phone."

Being part of a 'care-network'

Co-ordinating with others (family, neighbours, paid carers) can support care at a distance - although these arrangements can be fragile:

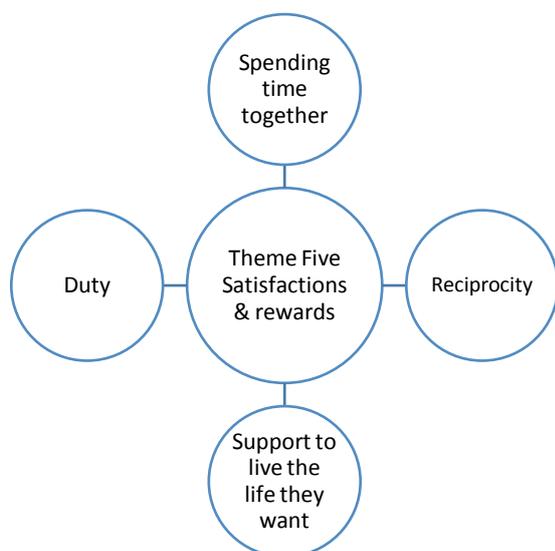
"Current care agency is great, have experienced two others who were not as good."

Relocation

Some carers or their relatives make a geographic move, so that they live closer together. However, there were dilemmas associated with this strategy:

"Wish she was closer as I feel it would be simpler & could be part of her life a bit more but she has lived there a long time and it would be unsettling / possibly unfair to move her."

5. Rewards and satisfactions



Satisfactions and rewards

Although carers identified difficulties and challenges, they also identified positive aspects of their caring role, these included:

Spending time together

The pleasure of spending time in each other's company:

"Being able to enjoy her company and appreciate her in her old age."

Reciprocity

Satisfaction at 'repaying' care provided in the past by their relative:

"It is good to be able to give back just a tiny bit of what she has given me all my life. She was and remains a good mother."

Helping the person they support live the life they want

This included supporting the person to live in their own home as long as possible:

"I am proud that purely thanks to me and my efforts my Dad can live where and how he wants."

Duty

Not all relationships were easy, and care was sometimes provided out of a sense of duty:

"Not really satisfaction - it's more a feeling of doing my duty"

Key issues emerging from this study

This research explored an aspect of care which has to date received relatively little attention; that of providing help, support and care from a distance. This research identified that many distance carers are spending a considerable amount of time in providing help, care and support, carry out many different types of care, and that they are an important source of support. Whilst the precise number of carers falling into this category in the UK is unknown, we suggest that this is a significant group of carers, who should be included in discussions and consideration of carers' needs and experiences.

Distance carers and those who live with or close to the person they support may share some experiences. For example, both groups may experience worry, financial costs and an impact on employment. However, the nature of these experiences or impacts may differ – for example for distance carers' worry may relate to factors such as not being able to drop in and see the person, or to respond quickly in an emergency; financial costs to the costs associated with travelling what were, in some cases, considerable distances.

Additionally, the research also identified some distinct issues and challenges, which appear to be specific to distance carers. These include the demands of travel, which may impact on carers' finances and energy; the challenges associated with living in a different locality, which may affect carers' abilities to access services and support. The research also identified some key strategies and supports which may facilitate distance caring. The use of technology, membership of a care network, and relocation all appeared to have the potential to help; however it was evident that there were difficulties and dilemmas associated with each of these strategies, which as a result we consider to be 'fragile

solutions,' which are at risk of breaking down, changing or not working in certain situations. Over and beyond these three key, but fragile, strategies, carers also provided advice for other distance carers. This is summarised below.

It is important to note that, while reporting difficulties and challenges, many distance carers reported experiencing rewards and satisfactions and appeared committed to their relative and to the provision of support. In the context of this commitment to caring, which co-existed with distance related difficulties and challenges, it is important that health and social care agencies, policy makers and carers' organisations recognise and respond to the contribution and needs of this distinct group of carers.

We note that in this research we were not successful (despite our attempts) at capturing the experiences of male carers, and of carers from BME communities. However, we are certain that both are represented among distance carers to a greater extent than within this particular study. Similar future research will need to explore ways of reaching these carers, ensuring that their perspectives are represented.

Advice from distance carers

Carers were asked what advice they would share with others in a similar situation. The main areas of advice are listed below:

Look after yourself as much as possible (although finding the time can be challenging)

"This situation is likely to be a marathon, not a sprint so pace yourself. Take up any help, support or advice offered at the earliest opportunity."

"Recognise that you are doing your best. There are only so many hours in a week. Also-try to find a little time for yourself."

Build up local sources of support

"Take advice from the local social work team and build a relationship with care providers. Meet with neighbours and go and talk to them when you visit. A bunch of flowers also works well."

"Have regular contact email, text, phone calls with paid carers and listen to them as they are the people visiting, recognising the subtle changes, they are your eyes and ears!"

"Find a local support group for relatives, even though you don't provide care in the local area."

"Build a relationship with their GP and formal carers. Talk to the formal carers and GP at least once a month (often my parents miss out on telling me the stressful times they've had)."

Consider introducing technology early on

"Incorporate as much technology as possible in advance - when the person needs to use it, it can be too late to introduce a new way of doing things."

Keep in touch regularly with the person you support

"Phone at the same time every night, even if there's nothing much to say. The sound of a loved one's voice is very important."

Set up a Lasting Power of Attorney early on, so that it is in place if and when needed

"Make sure you have Lasting Power of Attorney as soon as possible and make sure that neighbours, friends, service providers all know that you have LPA and will contact you before making decisions."

Have a back up plan

"You need back-ups and contingencies - provided through a good quality care company and/or other relatives/friends."

"Have a back up plan and make sure you take a break yourself now and again."

Acknowledgements and thanks

The researchers would like to thank all the carers who took part in the research from across the UK. The research has highlighted how busy distance carers are; thank you for your generosity in making the time to contribute to this research, and to increase our understanding of the experiences of this group of carers.

Thank you also to the many organisations and individuals who helped us to publicise the research, ensuring that people were aware of the study and had the opportunity to participate.

If you have any queries about any aspect of the research, or you would like any further information, please contact Caroline White on c.white@hull.ac.uk

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