CONNECTING CARERS

Exploring the potential of digital technology to alleviate experiences of loneliness and social isolation

UNIVERSITY OF BATH

IPR Institute for Policy Research

LIDA Loneliness in the Digital Age
What is the LiDA project about?

Loneliness in the Digital Age (LiDA): Developing Strategies for Empathy and Trust is a collaborative, multi-disciplinary research project that seeks to map and understand different experiences and responses to loneliness and to explore the potential for creative digital interventions to help manage those experiences.

Using a mix of qualitative, quantitative and co-design methods, LiDA has worked closely with three communities who are likely to experience loneliness linked to their life or work situation; (a) students leaving their home country or town to study in a UK university, (b) remote workers, and (c) informal carers providing care for a spouse, parent or other relative.

This document reports the project’s findings in relation to informal carers.

LiDA started in September 2014 and will finish in May 2018 and is led by Loughborough University in collaboration with partners at the University of Bath, the University of Exeter, and Northumbria University.

A broad range of expertise is brought into the project from Social Psychology and Health Psychology to Design, Human Computer Interaction, Computer Science and Drama.

LiDA is supported by the Economic and Social Research Council (ESRC) «Empathy and Trust in Communicating Online» (EMoTICON) program, with additional funding from the Arts and Humanities Research Council (AHRC), the Engineering and Physical Sciences Research Council (EPSRC), the Defence Science and Technology Laboratory (Dstl), and the Centre for the Protection of National Infrastructure (CPNI).
Executive Summary

What is the situation?
Taking on a caregiving role is a major life change that can disrupt one’s status of social life. Although providing care to a loved one can have positive effects, such as an improved sense of purpose and meaning in life, becoming an informal carer troubles people’s daily life and routines, roles and identity, finances, and sociality. Indeed, the strain of caregiving makes carers vulnerable to physical and psychological ill health. Loneliness and social isolation are major challenges reported by 8 in 10 carers in the UK.

What did we aim to do?
We wanted to find out about the day to day experiences of carers and understand about the times when they might feel lonely. We also wanted to work with them to help us develop creative technology that strengthen carers’ social interactions and help provide experiences of being supported and understood.

What did we do?
First we carried out individual interviews with sixteen carers in order to understand the experiences of loneliness and social isolation linked to their caregiving situation. We then ran a number of co-design workshops with these same people. These workshops brought the carers together as a group, and used creative methods to help build upon the issues raised during the interviews.
A follow-up workshop was then held with activities that explored new channels of communication between carers. This work helped us design a digital prototype called «ChatR» which aimed to provide a voice-based radio-esque forum for sharing experiences and know-how among carers who are rarely able to physically meet up. In a short pilot study we gave eight of our ChatR prototypes out to carers to explore the ways they might use it to provide peer support. In parallel, we also conducted a cross-sectional survey among carers and non-carers to examine whether experiences of empathy and trust in both online and offline social interactions increase an individual’s sense of connection to a community and thereby reduce feelings of loneliness.
What did we find?

The in-depth interviews with carers revealed the multifaceted character of experiences of loneliness. Feelings of loneliness were linked to diminished social interaction, relational losses and deprivations, a shrunken personal space and dissatisfaction with the quality of existing social encounters. Feeling powerless, helpless and solely responsible for the cared-for person were also tied to being lonely.

The co-design creative workshops enabled us to expand on some of the issues discussed in the interviews. Despite the differences in their personal situations there were clear commonalities of caring: consistent demands on their time, the drain on emotional energy, and separation from others. One key finding was the great value the carers placed on being able to meet and share stories and concerns with other carers. The interactions that they valued were empathic - providing opportunities to share and seek advice and to build a trusting relationship where the difficulties of caring could be discussed without feeling judged. However, it was clear that physically meeting on a regular basis was difficult; opportunities to meet with other carers were few and far between.

The pilot roll out of the Chatr device highlighted some potential benefits of providing voice-based peer-support among a closed community, and demonstrated how some participants felt comfortable sharing personal experiences and responding to the experiences shared by others. However, some felt uncomfortable sharing experiences without it being explicitly facilitated by the research team, while there were also challenges to providing timely responses to others because of the different temporal patterns and routines of carers.

Finally, the cross-sectional survey showed that online interactions that are characterised by empathy and trust can indeed reduce loneliness by increasing an individual’s social capital, both in terms of nurturing old bonds and fostering new connections to others.
What are the challenges for carers?

Carers in the UK: a few facts

- According to 2011 census data, 6.5 million people in the UK are carers.
- Estimates suggest that 9 million carers will be needed in the UK by 2037.
- The unpaid care provided by informal carers is worth an estimated £119bn per year.
- The majority of carers in the UK are people of working age; the peak age of caregiving is between 50 and 64 years old.
- 58% of carers are female, 42% are male.
- The majority of carers look after their parents or parents-in-law (40%), or their spouse or partner (26%). Another 13% care for children and one in ten carers (9%) look after a friend or neighbour.

Carers’ health

Carers are particularly vulnerable to poor physical and psychological health. For example, carers have higher levels of stress and depression and lower levels of subjective well-being than non-carers. They also face a greater risk of developing physical health problems. Having limited opportunities for social participation, means that carers can miss the psychological benefits that come from having social support.

Loneliness and social isolation in carers

Carers identify feelings of loneliness and social isolation as a significant part of their caregiving experience. Indeed, 8 in 10 carers in the UK have felt lonely or socially isolated as a result of their caregiving situation and research shows that carers report higher levels of loneliness compared to non-carers. Carers who feel lonely are also more psychologically distressed, more likely to develop depression, and have a low quality of life.
What did we do?

Qualitative interviews

In October and November 2015, we interviewed 16 informal carers to gain a better understanding of experiences of loneliness and social isolation linked to their caregiving role. The Bath and North East Somerset Carers’ Centre kindly helped us to access and recruit carers in the area. Interviewees were involved in a wide range of caregiving situations:

Eight participants were carers for their spouse; one young woman was caring for her partner; four carers were looking after a parent; and three were mothers caring for their child or children with significant health problems.

Seven participants were caring for somebody with dementia, six people were looking after someone with a physical illness, and the three mothers looked after children with a psychological or a developmental disorder.

All carers, except for one, were living with the cared-for person.

There were eleven women and five men; the youngest carer was 24 years old and the oldest was 91 at the time of the interview.
Creative co-design workshops

In March and April 2016 we invited all of the interview participants to take part in two creative co-design workshops. Twelve of the original 16 were able to be involved. We split the carers into three different groups and ran two workshops with each group. The first workshop involved carers in completing a series of open-ended, creative activities with one another, each of which related back to themes and issues identified in the interviews. These activities were designed to encourage the carers to reflect on their own likes and dislikes, the demands on their time, and how they saw themselves as a carer. Using a scrap-booking activity, the participants had printed prompts to think about and reflect on. These prompts included: «I am..», «I want to..», and «I feel I should..», giving the participants the opportunity to express their desires and wishes in order to help us identify possible areas where they might like support.

Another activity was called «magic machines». Participants were given the opportunity to design something that they felt would help them. It did not have to be possible in reality - imagination was the only limit on what they could create. These activities helped the carers elaborate on these topics, and find commonalities and differences in personal circumstances and experiences. After the first workshops, we gave carers a «cultural probe» activity to complete in their homes, where they took photos on a disposable camera in response to prompts we’d set in relation to their daily lives. We concluded with a final set of co-design workshops where participants reviewed each other’s photographs, and then completed a set of design activities exploring future technologies that would facilitate communication and community formation among carers.
Technology field trials

Drawing upon the insights gained through our interviews and the co-design workshops, we developed a digital prototype device that sought to provide carers with a means to continue to share experiences and provide peer-support to one another when physically separated. The prototype device – ChatR – in many respects mimicked a digital radio, with different channels for carers to skip through that provided different types of information and content. The content on most of the channels was intended to be created by the carers themselves, giving them opportunities to ask questions to each other, to give tips and advice, to talk about recent carer-related news or to tell stories. The prototype devices were given to 8 of our original carer participants for a short exploratory pilot conducted over a four week period.

Quantitative survey

Also, 72 carers (63 females) and 77 non-carers (29 females) took part in an online survey.

This complements our qualitative work by allowing us to test general relationships between different psychological states and processes. This method loses the nuances of individual experiences that is possible to achieve with the qualitative approach but allows us to ask valuable questions.

For example, do satisfying online interactions (i.e., those characterised by empathy and trust) actually make people less lonely, or are they unable to fill the gap in social relations that makes carers feel lonely?

To test this, we measured the number of face-to-face interactions, empathy and trust during online and offline interactions, online and offline social capital (both with regard to nurturing old and forming new social connections) and loneliness.
What did we find? Our analysis of the interviews resulted in four main themes which reflect the experience of loneliness in carers:

**Shrunken Personal Space and Diminished Social Interaction**

Carers' feelings of loneliness emerged in the context of shrunken personal space and diminished social interaction. Participants commonly discussed the restrictions that the caregiving role imposes, the lack of spontaneity, the constant preoccupation with the needs and well-being of the cared-for person and the challenges a carer faces to plan some time away from caring duties. These restrictions limited opportunities for social interaction outside the home but also time for self-care and leisure activities.

I miss going out with my friends, they all go all over the place still and they're all widows mainly. They do what they want and go out and enjoy themselves, which is right, but I can't do that because I can't leave him and I haven't got anyone to come and look after him. So that's difficult, I find that really difficult that I can't go out just when I want to.

(Female, 82, cares for husband).

**Relational Losses and Deprivations**

Carers also linked their loneliness to deprivations and losses with regard to important relationships. This sense of «losing» or «missing» something or someone was particularly experienced by spousal carers though occasionally carers also referred to losses and disruptions in relationships with other family members (e.g. grandchildren).

I'm going to use quite a strong word, I resent not being able to say, «We'll take [grandchild's name] away this weekend», it's everything has got to be planned and [resent] is a strong word, but I do.

(Female, 69, cares for father).

**Social Interactions and Distancing**

Social encounters characterised by some form of distancing and separation also generated loneliness. Carers described how a lack of understanding and empathy from others, ignorance of the challenges the carers face, and a lack of recognition and acknowledgment of their contribution can make them feel lonely.

I don't want to be self-pitying but it can be very lonely, that people don't really understand.

(Female, 48, cares for two children with disabilities).

**Powerlessness, Helplessness, and Sole Responsibility**

Finally, sentiments of powerlessness, helplessness and a sense of sole responsibility were linked to loneliness. Carers identified feelings of loneliness when they faced difficult caring moments and when help from others was not readily available, when they felt unable to alter and improve the cared-for person’s situation and when they felt that they were fully and solely responsible for that person.

And I think that's what, when I first retired, I did have a sort of loneliness of you can't share the duties. You see I've always been so used to sharing, team work but suddenly you realize that this mum is the person you've got to look after yourself. No-one else is going to put the rubbish out, no-one else is going to change the bed and that can become quite, «Oh dear, why do I have to do everything?»

(Female, 69, cares for mother).
Creative co-design workshops

Findings from the creative co-design workshops revealed several interrelated challenges faced by carers as well as valued experiences. These informed our understanding of ways to support people in dealing with loneliness:

Some participants described how they drifted into their caregiving role without necessarily realising it, often the result of slowly taking on more and more care responsibilities over time. Others experienced becoming a carer over a very short period of time which caused significant disruptions and ruptures in their lives. In both of these situations, however, it was often the case that it took some time for individuals to identify themselves as a «carer» and many were still reluctant to consider themselves in this way.

The workshops provided opportunities to expand on frustrations carers had with becoming distanced and separate from friends and family - sometimes through a lack of spare time, but sometimes through a feeling of lacking positive interactions with these people since becoming a carer.

Situations where individuals were able to meet with and talk to other carers helped to mitigate other frustrations. Seeking events and activities where other carers would attend was seen as hugely valuable, and the work of community organisations and carers charities was critical in enabling this. Meeting with other carers provided opportunities and safe spaces to talk freely, to be listened to and heard by like-minded others. These engagements with other carers were seen as highly empathic, and even though carers would come from very different experiences and circumstances there was a shared understanding and opportunities to find commonalities and connections.

Meeting with other carers also provided opportunities to acquire and share practical knowledge relevant to being a carer. Carers recognised that information and support services were available but felt they did not know how to access or act on these resources. Consequently, participants valued the opportunistic knowledge sharing that happened when encountering other informal carers. Information passed on by other carers was seen as authentic and trustworthy.

Meeting up with carers was also an opportunity to vent about worries and even to relax with people who would not be judgemental or critical. Many noted that in their day-to-day lives they found very few opportunities for their own pastimes and felt bad about complaining or moaning to other people about how tired, fed up, and upset they felt sometimes.

Carers recognised that the nature of being a full time carer means that there are very few opportunities to meet with one-another, especially given the diverse routines carers have and the necessity to prioritise the needs of the person they care for. This raises questions around the potential for technology to support this type of socialisation and chatter among carers without the need to be physically co-located.

Quantitative survey

The results of the quantitative survey confirmed our expectations that social interactions characterised by empathy and trust facilitate the maintenance of existing social bonds and the creation of new ones and thereby reduce feelings of loneliness. For carers, this was the case both for online and offline social interactions. For non-carers, this was the case for the maintenance of existing social bonds, but not so much for the creation of new ones. This underlines the importance of rich online environments for the creation of new social bonds among populations who, like carers, have restricted opportunities for face-to-face social experiences.
In response to what we found out in the interviews and co-design workshops, we built a prototype digital system called ChatR that was a bespoke designed for the carers we met during our research. ChatR is a small handheld device that is akin to a digital radio. It provides a number of «Stations» which the user can switch between. Most of these stations allow carers to contribute their own recordings. Each station provides access to different types of content – for instance, one is called «Tips and Advice», which is where a carer can leave a tip related to being a carer. Another channel is called «Questions and Answers», where carers can put questions to other ChatR users. Most of the channels allow people to respond to the recordings of others, while it is also possible to «like» and «give empathy» to specific recordings as a sign of appreciation. ChatR also has one channel that is primarily around carer related news – for this channel, the devices find information and news off the Internet on a daily basis and ChatR automatically reads it out when tuned to this channel.

We did not create ChatR to necessarily resolve issues of loneliness and social isolation for our participants. Instead it was used as a «technology probe» to help us further understand the patterns of lives and routines of our carer participants, and to explore ways in which audio and voice based technologies might in the future support new fora for distributed communities to share experiences with one-another. At this stage, we are most interested in understanding how carers might react to a technology or digital service like ChatR, what works well, and how it might need to be designed differently in the future.
Our initial exploratory pilot study of ChatR was primarily conducted to test the robustness of the system in a "real world" situation, and to also gather initial impressions and feedback. These were short (4 week) trials to begin with, yet despite several functional difficulties with the prototypes there were initial points of learning that we are taking forward into the next iteration of ChatR. These are initial early and provisional themes from our trials which are still in progress:

A. Some of the carers saw the potential benefits of providing voice-based peer-support among a closed community, but only if they were aware of who else was participating in the use of ChatR. In other words, it appears having existing bonds or connections with those you share experiences with via voice and speech is of critical importance. It is important to know that you are sharing with people whose experiences resonate with yours.

B. If a carer were to post a recording to a station to share a personal situation or to seek advice on an issue, other participants often felt compelled to respond as they did not want there to be a risk that the carer was not heard or listened to.

C. While many could see the value of the sharing of experience via voice and talk, there was some hesitation from carers when recording what they wished to say. Some would feel compelled to "prepare" what they wanted to say before recording it, and were worried about how their voice would sound to other carers.

D. Some carers felt very uncomfortable sharing experiences when not explicitly being facilitated by the research team. ChatR was designed in a way that all content would be generated by the carers without the researchers’ interventions; however, it became clear that the research team need to play an important role in suggesting topics of discussion, to stimulate responses to questions to help sustain engagement over time.

E. The different temporal patterns and routines of carers sometimes made it challenging to give timely responses to one-another, despite the desire to ensure people who had recorded messages had replies. Furthermore, the way ChatR was designed made it hard for the carers to find "new" broadcasts from other carers, and also meant they became worried that old messages that were not responded to would fall down the playlist and be forgotten about.

F. Some participants felt very uncomfortable with the idea of talking with other carers that, despite the workshop interactions, were still considered as "strangers."

What happens next?

We are currently redesigning a second version of ChatR and we will test this with our carers.

We will continue to report the results from our project and to link up with the key stakeholders that work day to day with carers.

We hope to continue this work and we will be looking out for other funding to enable us to do this.
Our published articles


Abstract: Although providing care to a family member or friend may provide psychological benefits, informal (i.e., unpaid) caregivers also encounter difficulties which may negatively affect their quality of life as well as their mental and physical health. Loneliness is one important challenge that caregivers face, with this psychological state being associated with morbidity and premature mortality. Although previous research has identified loneliness as an issue associated with being an informal caregiver, there is a paucity of evidence that attempts to understand this phenomenon in depth. This study aimed to examine informal caregivers' reflections on, and accounts of, experiences of loneliness linked to their caregiving situation. As part of a cross-sectional, qualitative study, sixteen semistructured interviews were conducted with 8 spousal caregivers, 4 daughters caring for a parent, 3 mothers caring for a child (or children), and 1 woman looking after her partner. The cared-for persons were suffering from a range of mental and physical health conditions (e.g., dementia, frailty due to old age, multiple sclerosis, depression, autism). Data were analyzed using an inductive thematic analysis. Experiences of loneliness were described by reference to a context of shrunked personal space and diminished social interaction caused by the restrictions imposed by the caregiving role. Loneliness was also articulated against a background of relational deprivations and losses as well as sentiments of powerlessness, helplessness, and a sense of sole responsibility. Social encounters were also seen to generate loneliness when they were characterized by some form of distancing. Though not all sources or circumstances of loneliness in caregivers are amenable to change, more opportunities for respite care services, as well as a heightened sensibility and social appreciation of caregivers' valued contributions could help caregivers manage some forms of loneliness.


Abstract: Care provision in many nations increasingly relies on the work of informal, or non-professional, carers. Often these carers experience substantial disruptions and reductions to their own sociality, weakened social support networks and, ultimately, a heightened risk of social isolation. We describe a qualitative study, comprised of interviews, design workshops and probes, that investigated the social and community support practices of carers. Our findings highlight issues related to becoming and recognising being a carer, and feelings of being ignored by, and isolated from, others. We also note the benefits that sharing between carers can bring, and routes to coping and relaxing from the burdens of care. We conclude with design considerations for facilitating new forms of digitally mediated support that connect those that care, emphasising design qualities related to transitioning, talking, belonging and escaping.

Access to the article: http://eprint.ncl.ac.uk/file_store/production/238541/F00CA686-B5EF-4A93-B3A0-913EFD680DDE.pdf
References


