Connecting Those That Care: Designing for Transitioning, Talking, Belonging and Escaping

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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.

Author Keywords

Carers; informal care; co-design; qualitative study.

ACM Classification Keywords

H.5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous;

INTRODUCTION

Informal carers are those who provide care and support for another dependent person, often a family member, partner or spouse. These duties are performed outside of, or in support of, organised professional care. As a result of the demands of the care role, carers can experience disruptions to their life due to changes in frequency of contact with family, peers,

friends and other social networks [35]. Related to this, it has been noted that informal carers are at heightened risk of experiencing social isolation [1, 22]. Researchers in the field of HCI have identified informal care as a challenging yet valuable space for technology design. Previous work has questioned how carers might, through technology, better manage their own health and wellbeing while still helping others [10, 23]. Others have highlighted how technological social support for carers should be multi-dimensional, providing ways to find others caring for people in similar circumstances, to identify opportunities to seek and share advice, as well as emotional and informational support [41, 42]. Furthermore, carers face specific challenges associated with seeking support in ways that are respectful and sensitive to the person they care for [47] and the complex patterns and routines inherent in caregiving [37]. There is still little concrete understanding of how technologies might sensitively provide support seeking opportunities for carers, however.

We describe a qualitative study that aimed to understand the support seeking practices of carers and the barriers that they face in doing so. First, we conducted semi-structured interviews with 16 carers. These interviews sought to understand the transition to being a carer, and the relationships between carers and those that they care for, as well as any wider support network of friends, family and peers. This was followed by a series of 4 co-design workshops involving 12 carers. These workshops used a range of methods to validate and elaborate on the findings from the interviews, and explored more deeply the qualities and content of channels of support that the carers appreciated and desired.

We contribute to the growing HCI literature on informal care in four ways. Firstly, we extend previous work through synthesis of the experiences of a heterogeneous set of carers, in addition to providing new and deepened understandings of the transition to, and reassurance of, caring. Secondly, we highlight how practices of support that are facilitated by

existing technologies fail to address issues related to the experiences of becoming a carer, connecting with other carers, or seeking momentary respite from caring responsibilities. Thirdly, we present opportunities for new technology designs based on the qualities of transitioning, talking, belonging and escaping in relation to care. Finally, we contribute new evidence that socialising strategies of carers differ from that of the general population, and require differently designed technologies to support these.

BACKGROUND

Informal carers[1]—sometimes referred to as family or unpaid carers—can be defined as those who care, unpaid, for family or friends on a full-time basis. Carers are a large and growing population—it is thought there are 44 million informal carers in the United States [8], and informal carers provide 80% of all care in Europe [24].

There is a growing body of research studying the impact that taking on care duties can have on an individual (e.g. [12, 15, 43]). Published literature has broadly highlighted the invisible, and often unrecognised, work of carers, the substantial contributions they make to the economy, and identified a range of health and wellbeing problems they can face. A consistent finding is that many carers feel disconnected from other people, including the person they care for. Carers can have limited opportunities for informal, spontaneous or meaningful socialising with others [37]. Likewise, they can experience a lack of freedom and flexibility, with daily routines generally organised around care duties. Tixier and Lewkowicz [42] examine the social support practices of older carers, noting that they cherish opportunities to talk with others who may be living in similar circumstances. These opportunities to talk were seen as venues to share advice and knowledge with other carers, with informal meet-ups and support group sessions seen as particularly valuable. However, the authors [42] also note that such groups can suffer from limited participation, perhaps again due to the routines and priorities surrounding the care of the family member or friend. The authors also highlight wider social and structural challenges—such as a lack of public places where those with disabilities or health conditions can visit, or a lack of state support for respite care—that further intensify these challenges.

A further challenge is that many people do not necessarily self-identify as carers. Gooberman-Hill and Ebrahim [20] note that this is reflected in how 'informal carers' often express their 'care' duties as simply changes or adaptations to existing relationships with spouses, family or friends. Schorch at al. [37] also note that the experience of becoming a carer can occur over protracted periods of time, requiring negotiation of new roles within the family, which gradually become solidified and accepted. Alongside this, there is an additional sense of becoming the "care expert" over time,

which can reinforce views that others do not necessarily understand or appreciate the role of carers [37]. It is also noted that carers experience problems with close friends and relatives not fully understanding a care receiver's situation or condition [42]. This can lead to hesitation around opening up to others, especially relatives or close friends [47]. This web of complex issues—the inability to find like-minded others to speak to, the perceived lack of support from others, or simply a lack of recognition that they are in a caregiving relationship in the first place—can all influence and impact on the support seeking behaviours and opportunities of informal carers.

Technologies to Support Caregiving

Recent work in HCI has highlighted many of the above issues with a view to understanding the role technology might have in mitigating them. One area of research has attended to reducing some of the burdens of care work—such as reminder and information systems to avoid repetitive questioning [21, 47], tools to share information between care receivers and networks of carers [14], remote monitoring and awareness systems [45] and technologies to avoid disruptive sleep [17]. Others have identified how technology can support carers in seeking emotional and informational support. Based on their study of familial carers for people with depression, Yamashita et al. [47] suggest a range of ways that online platforms might provide both social and anonymous spaces to share concerns and seek advice, as well as providing a means for new and experienced carers to share knowledge and skills. In a similar vein, Tixer and Lewkowicz [41] note that online networks for carers should acknowledge the heterogeneity and specificities of carers' situations by connecting those in similar circumstances. They note the importance of storytelling and experience sharing, which can be used as a way of connecting with similar others. Hensely-Schinkinger et al. [23] further note that those in the early stages of caring are more likely to seek support from more experienced carers, while those with more experience provide tips and advice. As such, much of the literature on support seeking strategies by carers echoes that of the literature on online health communities, where involvement in such communities supports the expression of anxieties to others in similar circumstances [32].

Although there is a growing literature on the benefits of online communities and social networks for carers, there have been relatively few studies of the specific ways they might scaffold the expression of concerns and peer-support. An exception to this is Fuentes et al. [18], who developed the Ohana system to aid mothers who caring for a child with terminal cancer document, express, review, and share their emotions. They note the ways that private reflections provide a means for opening up and sharing emotional difficulties with others in similar circumstances. This also echoes work on online health communities, where Chuang and Yang [11]

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[1] While this term has its challenges due to assumptions that the care is not as formal as other forms, or of a different standard, we have adopted the term for this paper as our study engages carers who assist their loved ones personally in a number of ways.

noted that changing the modality of communication—for example from a public forum to journals with configurable visibility to others—significantly altered the type of support users looked for. Forums encouraged support of an informational and factual nature, while journals encouraged 'nurturant support'—'expressions that show signs of listening, expressing sympathy, or expressing the importance of relationship' [11, p4]. Likewise, Massimi [33] notes that online social networks are valuable in supporting: connection with others like one's self and offering opportunities to vent; and that persons may find value in offering support to others experiencing challenges they have previously faced themselves. Massimi et al. [34] further highlight the opportunity that such communities provide for 'giving back'; in that they provide a means to 'repay their debt by listening and offering support'.

This previous work highlights the complex nature of technologically-mediated social support networks, requiring provision of factual information, experiential advice and emotional support, alongside opportunities to be heard and to listen. However, while there is a large body of literature that speaks to the potential of online communities and social networking services to support carers, there are very few examples of what these might look like or how they may be used in practice. Furthermore, recent work has highlighted the importance of online activities primarily supporting offline, in-person activities between carers —such as co-ordinating and planning of group meet-ups and joint leisure pursuits [42]. Again, there is still a relative lack of understanding how these might be supported and, critically, the forms and channels of communication through which this support might be provided and desired. The work described in this paper set out to examine these issues, complementing and extending this prior work.

STUDY DESIGN
This work forms part of a larger multi-disciplinary project examining the experiences of social connectivity and support seeking among a range of different populations. This specific study focuses upon understanding the support seeking strategies and experiences of informal carers in the South West of England (UK). It involves researchers with backgrounds in qualitative health research, participatory design, storytelling, social psychology and computer science. The work employs a qualitative lens to explore support seeking, aiming to develop rich, detailed, nuanced, and attentive-to-the-context accounts of the phenomenon of interest. To achieve this comprehensive and rounded examination, multiple sources of evidence are used including

interviews, workshop activities and probes. In the following sections we detail our study design, which aimed to: (i) understand the support seeking practices of informal carers; (ii) examine the barriers they face in seeking such support; and (iii) explore the design of technologies, with carers, to address these issues.

Participants
Participant recruitment was conducted in collaboration with a charitable carers centre that provides a range of services for carers living within its vicinity, including information and advice related to access to care services and financial support, counselling services and peer-support groups, and volunteer-run befriending schemes. Many of these services are provided by local volunteers, of whom many have been carers themselves. The centre provided a physical space where adverts for the project could be displayed, and posted invitations on our behalf to carers agreeing to be contacted regarding projects involving the centre[2]. Following this, the qualitative health researcher (who conducted the interviews) arranged a suitable time and location for the interviews. Following the completion of interview, participants informed us if they wished to continue participating in later stages of the study (the workshops).

We recruited 16 participants (11 female, 5 male), with an average age of 63 years old (youngest being 24 and oldest 91). All self-identified as carers. This diverse sample of participants was recruited to represent a heterogeneous informal carer population; nine provided care to a partner or spouse (Anne[3], Barry, Carl, Denise, Edna, Jade, Ken, Lee, Mike) four to a parent (Fiona, Gina, Harriet, Irene), and three to a child with a disability or mental health condition (Penny, Rose, Sue). The participants also represented a diverse set of experiences and expertise with digital technologies; five reported only basic familiarity and use of e-mail and SMS messaging, and five participants made more extensive use of VoIP (e.g. Skype, Apple Facetime) and Facebook. However, six stated that they rarely to never use digital technology. To capture a range of perspectives and reflections on experiences of caring, we employed several methods of data collection with each stage informing the direction and focus of the following stage.

Interviews
Initially, semi-structured interviews were conducted with each participant. These aimed to understand each person's background and experiences of caring. At participants' individual requests, 11 interviews were conducted in the carers' homes, 3 at a local University campus, and 1 at the carers centre. Interviews lasted on average 60 minutes (25 to

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Figure 1: Participants engaging in (from left to right): (a) "hands on" making of magic machines; (b) talking through their probe returns; and (c) creating the front page of their carers newspaper.

90 min) and were divided into two parts. First, participants were invited to discuss how they entered the caring role and what this involved, the main challenges they had faced, the felt impact these had on their life, and the channels of support available to them. Second, they were asked to reflect on their experiences of loneliness and isolation, how they coped with such experiences, and the role technologies held in relation to these.

Co-design Workshops and Cultural Probes
We invited the original participants to a series of design workshops to further explore the issues from the interviews. Due to the intensity of their care routines, or decline in their cared-for's health, 4 of the interview participants chose not to take part in this phase. We thus had a total of 12 carers, split into 2 groups (a group of 5 and a group of 7). Workshops lasted 120 to 180 min, and were held at a local University campus (agreed with participants as the most accessible venue). Each group attended 2 workshops which are now described.

Workshop 1: Scrapbooking and Magic Machines
The first workshops were divided into three activities. Initially, participants introduced themselves to the group and said a little about their personal caring circumstances. After this, participants were provided with prompts to choose from and invited to create a scrapbook page of images, text and material that responded to them. The prompts were derived from statements from the interviews, such as: "Sometimes I need…", "My home is…", "As a wife/father/etc. I want…". Participants were provided with a range of materials such as paper, stickers, coloured pens, etc. and encouraged to respond as they liked and to address as many or as few prompts as they wished. Participants were then asked to share the reflections they felt comfortable talking about with the group. Next, participants were placed into groups of two or three and invited to create 'magic machines' [2, 6]. Following [2, 6], the activity emphasised technology to be a 'magical unknown' and focused participants on material making rather than the feasibility of an idea. We asked the participants to imagine they were transported through time from 2116 to the present day, bringing with them a device used by carers of the future to communicate with one-another. Participants were given a range of materials (cardboard, stickers, shapes, wire and stick on buttons) and

asked to assemble their machine (Figure 1a). Once they had created their machine, the researchers questioned them on what it was, asking them to physically demonstrate it to the rest of the group (Figures 2a and 2b).

Cultural Probes
At the end of the first workshop, cultural probes [19, 13] were provided to participants. The probe pack comprised of a customised disposable camera with 14 prompts. In the spirit of past probe studies, the prompts were intentionally ambiguous and open to interpretation, aiming to serve as 'inspiration' for participants [19]. Again, the prompts responded to the insights from the initial interview. For example, one prompt invited the participant to photograph *"something that is a source of comfort"*. Another requested them to take a photo of *"something that helps you"*.

Workshop 2: Radios and Newspapers
The second workshop was divided into three activities designed in response to the discussions from Workshop one. Participants were split into groups of two and three. First, each group viewed their responses to the cultural probe activity and were prompted to choose some of their responses to discuss and compare with one-another (Figure 1b). After this, each group was provided with an image of a blank AM/FM radio and invited to create stations that might feature specifically for carers (Figure 2c). This activity was intended to further probe the 'channels' of support participants may wish to tune in and out of. At the end of this activity, the "radios" were swapped between groups and participants instructed to choose a "station" they found interesting. After this, those who created this station were (to their surprise) asked to role-play the station as though it were real. Finally, participants were invited to create the front page of a newspaper for carers. This included the paper's name, feature stories and regular sections (Figure 1c). Again, this activity was intended to probe the types of information and content that the carers deemed valuable to share with each other. The workshop closed with a short group discussion, reflecting on all of the completed activities.

Data Analysis
All interviews and workshops were audio recorded and transcribed, and material artefacts documented in photos. This data was treated as a corpus upon which we conducted thematic analysis. Following [7], data was coded at the

Figure 2: Completed co-design artefacts (from left to right): (a) Harriet wearing her Digital Bracelet magic machine; (b) Lee demonstrating his Robot magic machine; and (c) Rose's completed carers' radio channels.

sentence to paragraph level and then grouped together into themes. Given the iterative nature of our study, preliminary analyses were conducted following the completion of each of stage of data collection (e.g. following the completion of interviews, first set of workshops etc.) in order to inform the next stage of research. These codes and themes were then iterated, reviewed and extended through the subsequent stages of the study.

FINDINGS

We present our findings of this analysis below. Throughout, pseudonyms have been used to protect the identity of participants, which we append to quotes along with I (for interview) or workshop and group number (e.g. W1G1) to distinguish sources of data.

Becoming a Carer

From the outset of our interviews, participants explained how, on reflection, they drifted into their carer role without necessarily realising it, and thus failed to identify themselves as a carer for some time. Many reported that the nature of the condition of the person they cared for meant that their responsibilities were initially relatively small but grew as ailments progressed: *"over time, the role's just fallen to us, we've just taken on more and more and more"* (Harriet, I). For a smaller number, however, the care role was experienced as being *"thrust upon"* them (Irene, I), often due to a sudden event in the life of a partner or family member. In these cases, there was often a deep-felt unpreparedness for the role: *"there wasn't much warning it was going to happen, or conversation about what it meant for me."* (Denise, I).

The experience of becoming a carer was often marked by adherence to strict routines. Days were reported to be structured around regular tasks (such as bathing, shopping, preparing meals), with periods of inactivity purposely scheduled in to account for unexpected events: *"I have to always leave a lot of time"* (Irene, W2G1). Visits to shops were described as fitting very specific patterns to mitigate against any sort of unpredictability: *"I haven't bothered to go* [there] *because I thought, oh I can't do it in that two hours"* (Anne, I). As such, the transition to identifying oneself as a carer came with a realisation that one's life was becoming more routinised, less flexible and more organised around the schedules of others.

Opportunities to leave the home for anything other than shopping or other routine elements of the day were often very limited, but were appreciated where possible. For example, Barry recounted how he actively sought opportunities to take his wife out, and in doing so benefitted himself by *"bumping into"* people he knows:

"I do take my wife out to lunch as many times as I can because I think the extra stimuli of going out is a good thing for her […] *and you make a few friends when you go to one place regularly, don't you, or acquaintances, if not actual friends."* (Barry, I).

Barry's story was rather uncommon, however, and typically the routineness and intensity of care work was described as placing significant restrictions on personal freedom. Becoming a carer came with reductions in making spontaneous decisions around doing things, especially out of the home. Opportunities for socialising had significantly reduced for many participants: *"I miss not being able to go out with my friends. I can't just go out and stay out for the day because I can't leave him"* (Anne, I). Offers to meet with friends were often sacrificed to provide care, which led to feelings of loneliness: *"the isolation is increasing because I'm having to drop activities in order to look after* [wife's name]*"* (Lee, I). Even socialising via social media, which might be assumed to be less time invasive an activity, was felt to be difficult to keep up with:

"So having less time means that I've got less time to socialise, and it means that I haven't got time to sit on Facebook chatting to my friends and things like that, so I feel like I'm less in the loop with my friendship group and stuff like that." (Denise, I).

The prioritising of the care role also comes with a feeling of exhaustion that means that when a rare opportunity to see others does occur, participants tend to turn these down: *"I don't do much now. I'm too tired, I can't be bothered"* (Edna, I). Furthermore, in those rare occasions when participants did socialise they reported feelings of anxiety:

"We do make sure we try and get out on a Saturday but the horrible thing is when we come in, our hearts are in our mouths in case something's happened. So all the time we're thinking, "We've got to get back for [father]*"."* (Harriet, I)

It was clear that the experience of becoming a carer was one where the needs of the cared for were felt to be prioritised. The carers' focus was on helping the person they cared for in

the *"here and now"* (Lee, W1G1), that it was *"their duty"* (Sue, W1G1) and that all that mattered was *"their comfort"* (Denise, W1G2). Participants had started to feel as though they had lost things in their lives that were important to them; they had stopped working, lost contact with old friends and given up pastimes and hobbies. At the same time, while occasional frustrations surfaced, this was never held against those they care for. Indeed, it was considered normal to have an ever-present concern for their loved one's comfort and welfare, even if this was to the detriment of their own contact with others.

Distancing and Not Being Heard

Many of the participants referred to the ways in which their opportunities to talk to and communicate with others were very limited. Some explicitly referred to the problems they faced talking to the person they cared for, who was typically the person they spent most of their time with. This was a particular challenge for participants who cared for family members with communication difficulties: *"I tell him things and the minute I've told him it seems to have gone. […]he keeps very quiet. Unless I talk to him he doesn't really make any conversation."* (Anne, I). Similarly, Denise noted that she felt: *"like the only person I get to talk to very much is him* [her partner who she cares for] *a lot of the time he thinks that I'm not a carer and he doesn't have any problems"* (Denise, I). These communication challenges led to additional feelings of isolation: *"I am on my own because she's not relating, there's no conversation other than the weather or the trees, perhaps a bit about the garden, something like that."* (Lee, I). It might be assumed that in light of these challenges, carers may receive more support from family and friends. Indeed, some participants explained how their family provided them with *"wonderful"* (Ken, I) support, frequently phoning them to check in and visiting when possible: *"I have a very supportive family […] obviously, I miss my wife's companionship but I don't think I feel lonely"* (Ken, I). However, the majority reported many barriers to conversing with family about the situation they and the person they care for found themselves in. There was a perceived lack of appreciation of the severity of a situation (e.g. underestimating the impact of illness) or the requirements of the care role (e.g. not understanding the amount of work or effort required by the carer).

It was appreciated that it is difficult for non-carers to understand the challenges carers face: *"It is difficult for him* [her Brother]. *He doesn't understand it at all, like I didn't when I started out"* (Anne, I). Many of the participants explained how they developed strategies to ignore the advice of family members or friends, or found ways to stop having to come into contact with them. Some, such as Denise, felt compelled to keeping in touch with the few people she still spoke to. However, this was experienced as a continued stress and worry for her, as she found it difficult to explain the complexity of her relationship with her partner: *"I feel like people don't understand what's happening with me a lot of the time"* (Denise, I). Views and opinions from outsiders were described as highly draining:

"The other thing that people do, you will say something and they'll make an assumption in their reply and it's wrong. You get to a point where you think I haven't got the strength to say you're wrong because I've got to back and rewind" (Harriet, I).

Therefore, many of the participants found themselves in a situation where those who were their primary means of social contact were also those they often felt most compelled to distance themselves and withdraw from. As Rose explained, this lack of social support distanced her and made her feel *"very empty and numb"* (Rose, I).

Reaching Out for Support and Distractions

Participants also described feelings of loneliness, isolation and even helplessness as a consequence of the limited contact they have with others. A small number of participants felt as though these feelings were inevitable, and did their best to repress them rather than resolve them:

"I feel lonely quite often but I think I can't do anything about it so just try and shake it off, don't think about it, because that would make me feel really depressed if I keep feeling that I want to do things and want to go out and I can't do it." (Anne, I)

Most of the participants however described strategies they had developed to prevent feelings of being alone. Denise explained how they would contact friends and family: *"I try and reach out to people. I try and message people and say "I'm feeling really lonely, are you around?"* (Denise, I). However, she went on to say: *"I don't really get a good response on that".* Penny explicitly referred to using Facebook as a means for getting attention from others: *"if I put something on there, someone is going to see it and make a comment or like it, "yeah I'm alive, I'm doing something""* (Penny, I). However, social networks were also seen as causing even greater feelings of isolation. Certain features of sites like Facebook exacerbated negative feelings through indicating people as "online" and available when in reality they were not, just as WhatsApp would show when messages had been read but not responded to; as such, participants described such services as a *"curse"* that can make the experience of *"reaching out"* with no reply more difficult (Harriet, I).

Participants would also try to engage in activities in their home to distract themselves, often temporarily, especially if they were feeling down or lonely. Many of these activities would be seen as ways of *"switching off"* for a short period of time. Carl would, for example, search for funny videos on the Internet: *"if I get really down I'll watch YouTube, dogs and cats and stuff like that, when they're fighting and crazy car parking stuff. Anything that makes me laugh, basically"* (Carl, I). Denise would go to forums and seek help: *"you can post on there saying like "I feel rubbish, can you show me pictures of cats", and people will dutifully send you pictures of cats"* (Denise, I). She would also spend a lot of time on catch-up television, watching *"things that try and cheer me up, so comedy programs and stuff like that"*. This sense of being able to temporarily escape through broadcast media was also used by Barry who expressed a *"reliance"* upon his TV.

The use of light-hearted media was echoed during the radio

channel activity in the second co-design workshops. Radio channels were named *"You are good enough FM"* (Denise, W2G2), *"Cheer up AM"* (Denise, W2G2) and *"Saturday live – upbeat and friendly"* (Rose, W2G2), inferring affirmation and support. Humour also featured as a source for participants to move away from their duties as a carer during the newspaper task. Participants suggested ideas like *"Cute corner: Here's a family of meerkats – but one has fallen over! Oh no!"* (Denise, W2G2), a weekly comedy section (Rose, W2G2), funny cartoons (Harriet, W2G1), while Lee (W2G1) dedicated the entire newspaper to carer satire, to the joy of the group. As such, there was a sense that while the newspaper was still seen as a serious endeavour, with many bits of advice and information contained within, it also needed to convey positivity and provide distractions from care as well.

Finding Commonalities with Other Carers

While there were many instances where participants faced barriers to communicating with relations and friends, having opportunities to talk with other carers was greatly appreciated. For example, Sue (I) explained: *"obviously, they're great because they know exactly, their children have got similar things to* [child] *so we're all kind of on the same wavelength"*. The opportunity to meet other carers was described as influencing participants to have a broader, more positive, outlook upon their own role: *"going to groups, talking to people, just the general experience that now I don't feel that everything is a burden"* (Carl, I). There was a recognition of how important it was to have safe spaces to build links with other carers. Mike highlighted this when he reflected on attending a (diverse) carer group event:

"When I did the photography course, one of the guys was looking after his wife and he was having a tough time […] it helped him just to be there and relax with other people and because he was in a sort of protective environment, he could say more openly about things or how he was feeling […] everybody there has got some sort of issue and they'll be different but there is a common ground. So there's an immediate camaraderie and bond between you and that's somebody else who hopefully, next time he sees you, feels a little bit of a connection and it's widened out his prospect of support." (Mike, I)

This sentiment was further evident during the workshops, where it was clear that participants simply appreciated having an opportunity to be with other carers: *"It's nice to be able to talk to other people"* (Anne, W1G1). The participants felt that the workshops had allowed them to share some of their challenges and concerns:

"I think this is incredibly helpful to be with other people in the same situation, even though our situations are different. They're not really, are they? We've all got one common thread that we've always got somebody else on our mind, haven't we? We always all feel responsible for somebody else in some way. I wish we could stay together as a group and meet up." (Penny, W1,G1)

Though many of the participants had rather different care roles and responsibilities, they identified and empathised with the stories of others: *"I'd like to say how much it's easy to relate to all these things, first of all."* (Irene, W1G1). Moments

where participants opened up were met with encouragement and words of advice from other workshop participants. Indeed, these would lead to extended discussions where they reflected on their commonalities, despite their different circumstances (W1G1):

Harriet: *"I struggle between feeling cross, guilty, & loving him."*
Penny: *"Yes. No, it's exactly the same with me and my daughter, and it's the…".*
Harriet: *"Yes, it's the emotions, isn't it that you go through as a carer?"*
Penny: *"It is. It's having an outlet that's really important, isn't it?"*
Harriet: *"Yes."*
Penny: *"This is great, being able to meet other carers."*

These exchanges between participants were free flowing and supportive in nature, with Fiona (W1G1) exclaiming it's *"so lovely to hear other people's confessions"*. Harriet (W1G1) elaborated further: *"it's only when you're with people who have the experiences that you feel able to say things"*. As such, taking part in the workshops meant she had felt *"safe to actually put things down on paper. I don't normally feel safe to put it on paper, but in this group, I have."*

Sharing Advice and Remotely Connecting

Having opportunities to be with other carers was also found to be valuable for very practical reasons. It was acknowledged by each participant that while there was an abundance of information available online about the types of support and services carers can access, understanding what this information means in practice was very challenging. Harriet (W2G1) explained how *"it's knowing the roots to these things and because if you don't know the routes and the process and the system, you can give up"*. Indeed, Lee (W1G1) exclaimed that much of the practical *"know how"* he had gained was mostly from fellow carers. He noted that when individuals start off as a carer they *"are searching in the dark, really, for these things"*, a comment that was affirmed verbally and through nods of agreement from others.

The sharing of practical advice and speaking from experience came through strongly in the radio and newspaper design activities. For example, during the radio activity one of the channels requested to be acted out was *"carers forum"*, which Mike and Harriet (its creators in W2G1) described as *"an information providing service"* (Figure 2c). As they began their improvised role-play, Mike and Harriet introduced the carers forum as a *"phone-in chat show"*. Fiona, who had requested the carers forum idea to be role-played, 'phoned in' and asked for advice about how she could find *"a good care home"* for her elderly Mother —an actual problem she was currently facing. Over the next ten minutes these three participants discussed this situation together—still in chat show guise—while other workshop participants started to also 'phone in' and offer their own advice based on personal experiences. At the end of the activity, Fiona remarked that the advice she received *"sounded so genuine as well"*.

The magic machine activities provided further means for participants to explore ways to communicate and express themselves. While this activity was broadly framed around a *"machine to communicate with"*, participants tended to respond with machines that would bring together fellow carers remotely. For example, Harriet, Carl and Penny created a digital bracelet (Figure 2a) that would allow for a continuous link to be established between people: *"carers are often invisible and alone. Even if you've not with people or you're in a room with others who are ignoring you, you're not feeling alone"* (Penny, W1G1). Similarly, Rose suggested her *"walking in other people's shoes machine"* (Rose, W1G2):

"I think we will need to have more empathy... we need to be able to understand other people's feelings, where they're coming from, what makes people tick... it would be able to scan me and work out how stressed I am or scan you and work out whether your cortisol levels are sky high... this could be used for everyday situations but also for our caring situations." (Rose, W1G2)

Others suggested machines that would report to others when your vital signs suggested you were distressed, or a device that allowed people to *"see you portray the emotion that you're going through"* (Lee, W1G1). While provisional and speculative, these ideas illustrated the importance that participants placed on technologies that supported the expression of feelings and new ways of accessing and communicating an individual's circumstances. Particularly notable was that the ideas all supported remote interactions, but in ways that were rich and multidimensional. Indeed, one of the continuing concerns participants expressed in the workshops was that the realities of being a carer meant that physically meeting with other carers —as they did for our study —is effortful, difficult to organise, or often impossible. Therefore, they privileged technologies that would mediate carer interaction, but in ways that were sensitive to the care context and offered greater sincerity than simply sending a message in text.

Finding Space to Relax

Along with the need to feel connected to others, personal time and space was also valued. *"Me time"* was often sought after, enjoyed as a short period of relaxation, and used to provide temporary sanctuary when circumstances become *"too much"*. The nature of this personal time was diverse. Gina (I) would simply have a *"lie down"* and *"go to sleep, […] I just go and get out of the way of everything."*. Sue (I) explained that she would *"go out to the garden and have a cigarette to calm myself down and then come back in and I feel more able to cope with it"*. Others would set aside specific times of the day for a small amount of relaxation: *"I listen to the radio a lot. […] I don't like lingering in my thoughts before I go to sleep. So, I try and ward off the feelings of loneliness by other voices and other sounds"* (Rose, I).

While escaping and needing time for oneself was viewed as essential, it was also steeped in feelings of guilt: *"I don't know about any of you, but sometimes I just feel incredibly selfish because I just want some time to myself"* (Denise, W1G1). Such feelings would manifest otherwise trivial events as something to be 'deserved': *"Like a cup of tea is not difficult... but I'll just be like "oh, I don't deserve it..."* (Denise, W2G2). These feelings supported self-doubts that to be a good carer you need to be busy all the time. While some participants would be deeply self-critical of their abilities and efforts as a carer, their dedication to their care receiver was clear to see. It is perhaps because of this that participants sought the time and attention of other carers so much; they could be there to provide advice and support, but also to tell them they are doing well, that they are not alone, and that it is acceptable to escape the care role when you need to.

DISCUSSION

While we have divided our findings into distinct themes, many of the issues are deeply entwined. Often, when an individual becomes a carer they experience a reduction in opportunities to socialise as everyday activities fit a care routine. Those meaningful social interactions that do occur become centered on a small number of people—relatives, younger family members, nearby friends. Very often it appears these interactions can, for some, lead to frustration and further withdrawal due to misunderstandings, disagreements or poorly received advice. While carers appear to find fleeting distraction and enjoyment through online and broadcast media, many express a need to talk with other carers. Those that care, often regardless of their specific circumstances, are seen to share values and experiences; belonging to a community of carers comes with opportunities to share stories, difficult experiences and information. It is a chance to feel as though you are not alone. Carers also reaffirm the hard work other carers do, and appreciate the need to escape from this work every now and then. However, opportunities to physically meet with other carers are rare due to the routines and work that promote isolation in the first place. These issues are further compounded as it may take some time for someone to identify as being a carer, and there is guilt associated with thinking about one's own self, health and wellbeing. Therefore, in many respects care needs to be publicly surfaced in order to make connections with others; but it also needs to be experienced in private spaces with those others who appreciate the circumstances one lives within.

We now reflect upon these issues as they relate to the design of future technologies that might connect those that care. We focus our discussion around four design sensitives: *Transitioning*, *Talking*, *Belonging* and *Escaping*.

Designing for Transitioning Into Caring

It was apparent that the experience of becoming a carer was not easily articulated by participants. It was seen to be an ongoing process of self-realisation and eventual self-identification. Identifying with being a carer came with the realisation that daily routines were habitually in support of another. It may also come with significant changes in personal circumstances that result from committing oneself to becoming a carer - such as relocating, retiring, temporarily leaving work, or no longer seeing friends and family or

pursuing pastimes and hobbies. It was also clear that transitioning came with a need to learn new skills and navigate complexities related to personal and family finance, state support, and the law. Based on our findings, we consider two areas for future design work to support in relation to transitioning into caring roles:

(a) Supporting making care public: Our findings reflect work in the social sciences on how self-identifying as a carer is a nuanced and dynamic process [25]. Identifying oneself as a carer can be challenging; carers may not see themselves as providers of care but instead helping and supporting a relative or friend [37]. Yet, our participants benefitted in many ways from self-identifying as carers as this enabled them to access otherwise unavailable resources and services. It also enabled them to recognise that there were others doing the same 'work' as them, to join support groups and participate in activities that were articulated as being beneficial. This reveals a challenge to HCI — how can a user-centered discipline reach those who don't (yet) identify as part of a target demographic? Furthermore, how is it possible to reach those experiencing such transitions when they have yet to reach out to support organisations? We suggest that we do not just focus on designing for 'the carer' as a user, but also exploit HCI's potential to 'make things public' and express matters of concern [16]. HCI has emphasised the value of not designing technologies at all [4] and critiquing simplistic solutions to complex and contested issues [6]. In this case, therefore, a direction for future HCI work might be to support advocacy of carers and made visible the work they do [39]. HCI could also be used to contest some of the socio-economic and structural challenges that shape carers' lives. In doing so, we might imagine that raised public visibility of carers would scaffold connections and awareness between those who have yet to self-identify and those who already have.

(b) Supporting mentoring: A significant issue for carers in transition was access to practical advice and information, echoing prior work on informational support for informal and family carers [9, 23, 40, 41]. As Vines et al. [44] note, it is not simply the provision of information that is important; it is the exchange of practical, hands-on know-how. While there may be an abundance of information 'out there', without scaffolding or interpretative support this was seen as having little value. As in [34, 23] our more experienced participants passionately wanted to give back to the carer community. Thus, designing ways that facilitate the mentoring of novice carers by those with practical experience is an important direction for future HCI work. While it may be assumed that traditional online forums might support these activities, such textual interactions would still require significant amounts of interpretation by those in transition. Therefore, we suggest remote mentoring practices be supported via the creation of richer how-to guides where carers talk through processes and experiences of navigating services and protocols. For instance this might be achieved by adopting video-mentoring systems currently used in

education (e.g. [30]), or by appropriating video-based narrative and storytelling platforms (e.g. [46]).

Designing for Talking to Other Carers
A finding from our study was the value that participants saw in talking to other carers. This offered respite and opportunity to reflect on their transitions. For those who cared for someone with a communicative difficulty the need for conversation was longed for and expressed not in terms of quantity, but quality. However, as noted in prior work [37, 42], carers have limited opportunities to socialise due to their busy days and short periods of rest. We consider two areas of design to related to this to offer future support:

(c) Support conversation and dialogue: While there was great value placed on conversation, the majority of work in HCI on caring tends to focus on the translation of such in-person talk to online environments (e.g. [10, 42]). It was clear though that, again, participants valued literally being able to talk with others like them. Conversation supported not just being listened to, but being heard and then hearing the experiences of others. The ways such talk supported experience sharing and emotional support was at its clearest in the enactments of radio stations, where personal situations were articulated, politely questioned, elaborated on and responded to. Conversing and going back-and-forth was particularly important as experiences and situations were often difficult to articulate and emotion laden. How these were uttered—with pauses, sighs, and being reworded—were critical in these dialogues and would be entirely lost by most forms of textual expression. Therefore, future systems should support this form of conversational talk, in all its richness—for example by making use of existing real-time IVR (Interactive Voice Response) technologies [27] or social audio [29].

(d) Support asynchronous talk: While talk and conversation is important, the restrictions on their time, opportunities to get out of the home, and individual routines means getting together to talk—even if mediated by digital technologies—would be challenging. Therefore, as well as supporting talk and conversation, we need to support it in asynchronous ways. We might imagine ways of appropriating and extending technologies used to support asynchronous audio messaging in education [26, 36], connect families over distance to receive messages at designated times [28] or recent work on connecting socially isolated elders with their remote families [3]. It is important, however, to considers ways for carers to navigate talk and to express themselves in ways that evoke conversational attributes (a common challenge with asynchronous audio communication [38]).

Designing for Belonging to a Community
There was consensus from the carers that they are "*all kind of on the same wavelength*" (Sue). Simply knowing you are not alone and that others are there for you was deeply appreciated. This has two implications for future work that seeks to support carers:

(e) Support diverse caring communities: The carers in our study self-identified as 'persons who care for another'. In doing so they recognised each other as members of a diverse community. While advocacy and support groups for broad populations of carers do exist, in HCI there is a tendency to focus on specific populations, such as family members with depression [47], parents of high-risk infants [31], and spouses with dementia [21]. This is in contrast to work that, like ours, broadly scopes the experiences of diverse communities of carers [37, 41]. Focusing on specific populations can, of course, lead to clear benefits around the specific support needed for specific conditions. However, doing so comes with an (understandable) preoccupation with that specific care role, rather than the wider forms of support carers may need, and may further restrict opportunities to build awareness and visibility of carers to each other. We suggest there is potential for connecting those who may, at surface level, have limited ways of relating to one-another. We saw that a mother of a child with a disability was able to connect richly with an older carer with a husband with dementia. This reframing might also focus attention towards the carer, rather than just towards the cared-for's ailment.

(f) Support intimacy and ambience: Our findings highlighted that while rich and substantial conversation was important, there were times when subtle forms of support were desired and more appropriate. This included gestures from others that recognised they had been listened to, thought of, or that they were *"alive"*. Indeed, Harriet's magic machine provided a continuous link to other carers to prevent feelings of being alone, yet made a 'callout' when in need of support. Taking this further, we might also imagine ways that activity between carers might be represented to support ambient awareness and presence; or perhaps provide ways of building anticipation to a looked forward to phone call or meet-up. While these forms of support may initially seem superficial they would clearly offer value to people like our participants who, much of the time, could not afford prolonged spells of socialising but longed for expressions of support at critical moments.

Designing for Temporary Escape

Our final discussion points relate to those moments when our participants needed to escape, even if temporarily, from their care duties. Sometimes these were routine; sometimes these were sudden and when a crisis was occurring or some down time was needed. We raise two final directions for future work that might support these moments:

(g) Support safe spaces: Bazarova [5] observes that intimate and honest messages can support relational closeness; however they also have the potential to be misunderstood, considered inappropriate or are problematic if disclosed to third parties. In our case, it was clear that there was a resistance to disclose certain things to family members or friends that participants were comfortable sharing with other carers. Therefore, the provision of safe spaces—which are accessible to only other known carers—could be of great value. Here we do not just advocate creating private, secure and trusted online spaces, but we urge research that explores the ways such spaces are accessed or physically presented in domestic environments (e.g., whether a device to access such spaces is visible on a sideboard, or hidden in a drawer).

(*h***)** *Support the person***:** Making space for sharing stories is important for building connections between people who come together around issues of health and care [11]. While many of our considerations relate to information needs and expressions of empathy and support, there is a need to engage with the 'person' outside of the care duties. Our workshops, while laden with exchanges explicitly related to care, were also successful in supporting participants to chat about upcoming TV shows, a film they'd seen recently or their favourite late night radio show. Although their lives were stressful, our participants still aspired to find periods to relax. Thus, technologies that support carers should offer opportunities for making connections with pleasurable activities people might normally wish to engage in; or find connections between people not based on ailments, but on their own previous biographies, interests or vocations.

CONCLUSION

In this paper, we discussed the practices through which diverse groups of carers connect with and seek support from others. We have surfaced a range of issues that carers face, including problems with finding space to be social, challenges with connecting with relatives and friends, and the joys of being with other carers. Yet we also show that the life of a carer is such that opportunities to seek time with others are limited. We have raised directions for the future design of technologies that seek to connect those that care. By designing to make care more public we may address some of the wider social and structural challenges that mean carers struggle to connect with others in the first place. However, we have also highlighted a range of implications for how digital platforms may support forms of communication that relate well to this group. In doing so, we draw attention to supporting transitions into becoming a carer and the formation of diverse and supportive communities. Future work should specifically address issues of supporting remote talk between carers in ways that do not simply focus on the practical challenges of care but on carers as valued, yet ordinary, individuals that need to escape, vent and be social.

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