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McSwiggan, Linda C.; Marston, Judith; Campbell, Martin; Kelly, Timothy B.; Kroll, Thilo

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Title: Information-sharing with respite care services for older adults: A qualitative exploration of carers' experiences

Authors:

Dr Linda C. McSwiggan, Senior Lecturer (Corresponding author)

School of Nursing and Health Sciences, University of Dundee

11 Airlie Place

DUNDEE, Scotland, DD4 0RG

Tel. +44(0) 1382-388534/ Fax. +44(0)1382-388533

Email. l.c.mcswiggan@dundee.ac.uk

Mrs Judith Marston, Health Visitor, NHS Fife, Scotland

Dr Martin Campbell, Senior Lecturer & Pro-Dean of Science, School of Psychology & Neuroscience, University of St. Andrews, Scotland,

Professor Timothy Kelly, Dean, School of Education and Social Work, University of Dundee, Scotland.

Professor Thilo Kroll, Professor of Health Systems Management, School of Nursing, Midwifery and Health Systems, College of Health and Agricultural Sciences, University College Dublin, Ireland.

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Abstract

Respite services play an important role in supporting older adults and their carers. When an older person is unable to fully represent themselves, provision of respite care relies on effective information-sharing between carers and respite staff. This study aimed to explore, from carers' perspectives, the scope, quality and fit of information-sharing between carers, older people and respite services. An explorative, cross-sectional qualitative study involving a purposive sample of 24 carers, recruited via carer support groups and community groups in voluntary organisations, was undertaken in North East Scotland. Data was collected from August 2013-September 2014, with participants taking part in a focus group or individual interview. Data was analysed systematically using the Framework Approach. The multiple accounts elicited from carers identified how barriers and facilitators to information-sharing with respite services changed over time across three temporal phases: 'Reaching a point', 'Trying it out' and 'Settled in'. Proactive information-sharing about accessibility and eligibility for respite care, and assessment of carers' needs in their own right, were initially important; as carers and older people moved on to try services out, time and space to develop mutual understandings and negotiate care arrangements came to the fore; then, once shared expectations had been established, carers' chief concerns were around continuity of care and maintaining good interpersonal relationships. The three temporal phases also impacted on which modes of information-sharing were available to, and worked best for, carers as well as on carers' perceptions of how information and communication technologies should be utilised. This study highlights the need for respite staff to take proactive, flexible approaches to working with carers and to make ongoing efforts to engage with carers, and older people, throughout the months and years of them utilising respite services. Information and communication technologies have potential to enhance information-sharing but traditional approaches will remain important.

Key words

Respite care, older adults, carers, information-sharing, information and communication technologies, qualitative research

What is known about this topic

- Respite care can have a positive impact on the lives of carers and the people they care for.
- Ineffective communication contributes to non-use of, and disengagement from, respite services.
- Carers need to feel confident and supported when handing over care to respite services.

What this paper adds

- Respite services need to work with carers throughout different phases of their caring journeys in order respond to changing needs.
- Proactive, facilitative conversations and actions of respite staff impact on carers' ability to inform respite care provision.
- Use of information and communication technologies to promote information-sharing with respite services would benefit from further exploration.

Introduction and background

Over the past two decades, the importance of respite care for family carers (hereafter referred to as carers) has grown across the developed world, including the United Kingdom (UK) (Lindsay *et al.* 1993, Scottish Government 2010, Department of Health 2012, Welsh Government 2013). Respite care is defined as ‘a service intended to benefit a carer and the person he or she cares for by providing a short break from caring tasks’ (Scottish Government 2014). Globally, governments and voluntary organisations provide various respite services for older adults - residential, in-home, day centre, one-to-one outings with support workers, and host family - reflecting greater appreciation that carers, and those they care for (hereafter referred to as older people), need breaks in different ways at different times and for different periods.

An estimated 650,000 people aged 65 years or over will be living in the UK by 2017 (Office for National Statistics 2011), many of whom will suffer from long term health conditions, such as dementia, coronary heart disease and stroke. It follows that, in absolute terms, the numbers of older adults requiring support and care from their spouses, adult children or both will continue to rise. In Scotland, there are well-established patterns of increasing total (overnight and day time) respite provision to support the care of older adults who have a range of increasingly complex physical, mental and social care needs (Scottish Government 2014). In addition, as people who use services have been consulted, greater emphasis has been placed on the quality of services and standards of care that older people and their families can expect to receive (Carers Scotland 2008, Scottish Government 2011a).

In the United States, United Kingdom and Australia, research has identified the challenges of providing effective respite care, not least in terms of encouraging uptake and ongoing engagement with services (e.g. Greenwood *et al.* 2012, Robinson *et al.* 2012, Phillipson *et al.* 2013, McPherson *et al.* 2014, Neville *et al.* 2014). Shaw *et al.*'s (2009) systematic review identified three recurrent themes: carers had limited knowledge about availability of respite services, reported feeling frustrated by the processes of being assessed for services and could not access services which met their expectations. In a literature review relating specifically to carers of people with dementia, Phillipson *et al.* (2014) identified similar contributory factors to non-use of respite services, including, limited access to information about services, misinformation, guilt and apprehension about handing over care, and dissatisfaction with quality of care. Research has consistently highlighted information-sharing across organisational and professional boundaries as crucial to overcoming many of these challenges. Whilst many older adults are able to communicate their specific needs, for those who are unable to do so, effective information-sharing relies on carers and respite staff.

From hospital and care home contexts, limiting factors to information-sharing have been identified, such as lack of time, lack of attention to detail, limited involvement of family members, lack of follow up, and tendencies to regard handovers as custom rather than meaningful activity (e.g. Nolan *et al.* 1996, Voss *et al.* 2011, Croos 2014). In contrast, active information seeking by staff, formal mechanisms for information-sharing and a single point-of-contact, such as a keyworker, have been identified as beneficial (Payne *et al.* 2002, Holly & Poletick 2013). However, studies to date have focused on the perspectives of those delivering services rather than those of care recipients; and on one-way care transitions rather than

temporary respite transitions. In addition, not enough is known about how information-sharing is negotiated to allow a purposeful flow of information between all parties (Wenger *et al.* 2002).

In our technology-driven World, there has been a significant shift in policy towards using information and communication technologies (ICTs) to improve and sustain provision of health and social care (Ham *et al.* 2012). It is proposed that the best way to exploit this ‘information revolution’ is for those commissioning and delivering services to work in partnership with individuals and families, locally and nationally (Scottish Government 2010, Scottish Government 2011b, Department of Health 2012, Welsh Government 2013). Research indicates that older people’s patterns and frequency of ICT use varies from that of younger adults (e.g. Olsen *et al.* 2011, Barnard *et al.* 2013, Yagil *et al.* 2013). Nevertheless, for many older people, ICTs (such as mobile phones, internet banking and emails) are gradually becoming part of everyday life and, in the future, are likely to extend further into management of health and wellbeing (Dickson & Hill 2007, Sayago *et al.* 2013). Within the context of respite care, understanding how ICTs might best support information-sharing between carers, older people and respite staff is, therefore, potentially important.

The aim of this study was to investigate carers’ experiences of information-sharing when responsibility for the older person they cared for was being handed over to respite services. In particular, we were interested in what respite staff could do to communicate information in a way that reassured carers and provided solid information about what would happen during respite care. Moreover, we wanted to learn about what, from carers’ perspectives, enhanced understanding among respite staff, about the older person they would be caring for.

Methodology and methods

As little prior knowledge exists in this area, an exploratory, cross-sectional, qualitative study was undertaken across two regions in North East Scotland. Potential participants were invited to take part in a focus group or interview. A key design feature was selecting a study setting which offered opportunities to compare and contrast carers' experiences based on characteristics that could be expected to influence these experiences. In this study we assumed that experiential differences may arise between urban and rural areas, and carers of different socio-economic backgrounds. This is not to say that other characteristics, such as age, relationship with the older person (e.g. child, spouse), single versus compound caring responsibilities (e.g. people caring for more than one relative), or duration of caring did not matter but these would require a larger study which could be conducted following this initial exploratory work. In line with a broadly social constructionist approach, it was anticipated that participants' narrations would be influenced by interactions within the study setting as well as past experiences and the contexts in which they lived and worked (Barbour 2014). Specifically, we focused on three research questions:

1. What barriers and facilitators do carers encounter when attempting to share information about older people with respite staff?
2. What modes of information-sharing work best from the carers' perspective?
3. How might the use of information and communication technologies (ICTs), such as multimedia devices, support information-sharing between carers, older people and respite staff?

‘Carer’ referred to a person aged eighteen years or over (relative or friend; not necessarily blood- or marriage-related) who identified her/himself as having responsibility for the care of an older adult who had limitations in their abilities to represent themselves. A broad definition of ‘information-sharing’ was utilised within this study, incorporating traditional information ‘transfer’ approaches (face-to-face meetings, telephone calls, paper-based tools) as well as more innovative approaches using ICTs (audio-visual diaries, Skype, texting) (Pentland *et al.* 2011).

Recruitment and sampling

Potential participants were accessed via carers’ groups and community groups; this included generic groups (e.g. residential respite carers’ group, Church singing group) as well as condition-specific groups (e.g. Parkinson’s disease carers’ group, Dementia cafés) (see Table 1). Our original intention was to recruit participants to focus groups. However, after several months we were struggling to recruit; two main reasons were identified - some carers did not wish to take part in a group discussion and some carers could not commit to the time requirements of a group meeting. Following discussions with our Advisory Group (which included representation from Queen’s Nursing Institute Scotland, Princess Royal Trust for Carers University of Dundee User & Carer group), we offered potential participants the alternative of taking part in an interview, with the aim of recruiting up to 20 participants. Recruitment subsequently improved.

Purposive sampling was utilised to recruit participants of different ages and gender, who had been caring for different durations and for people with a range of physical and mental health needs. To be included, carers must have cared for an older adult who had limitations in their abilities

to represent themselves (e.g. sensory and/or cognitive impairments) and have accessed residential, day centre, in-home, one-to-one, or host family respite services within the past year (see Table 2). Carers who self-reported that they cared for older adults who were fully autonomous in their abilities to represent themselves (e.g. older adults who have loss of motor function only) or had not accessed respite services within the past year were excluded from the study.

A member of the study team contacted carers' groups and community groups to ask them to facilitate access to potential participants. Following preliminary discussions, a study team member attended these groups to give an overview of the study and invite participation. The focus group or interview was subsequently arranged. Ethical approval for the study was obtained from the university research ethics committee (UREC13017).

Data generation, data management and analysis

Data generation took place between August 2013–August 2014. Through focus group or interview, participants reported age, relationship to older person, level of care provided and type of respite utilised. A detailed semi-structured topic guide was used to allow a focused yet open and flexible approach to data generation. With participants' informed consent, data were audio-taped and transcribed. Data analysis was based on the framework approach (Gale *et al.* 2013) and was an iterative process taking place alongside data generation and transcription. Thematic analysis was undertaken by two members of the research team (LMcS & JM). The other team members reviewed the coding frame and were involved in developing the analysis.

Findings

Twenty-four carers participated in the study (see Table 3). Seventeen participants were female and participants had been in caring, on average, for nine years (range 1-23 years). The majority cared for their spouse (N=15; 6 for their wife); nine cared for their mother (N=7) or mother-in-law (N=2). Most participants were caring for someone with a cognitive impairment (N=16); the remaining eight were caring for older people with sensory impairments, such as hearing loss or speech impediments. Four participants attended a focus group convened within a voluntary organisation; interviews were conducted with the remaining participants in voluntary organisations, university premises or participants' homes, depending on participants' preferences. None of the participants had experience of host family respite, and only four participants, all of whom had taken on caring roles within the last five years, had experience of one-to-one respite care.

From carers' retrospective accounts of information-sharing with respite services, three temporal phases emerged – 'Reaching a point', 'Trying it out' and 'Settled in' (Table 4).

Reaching a point

This first phase related to carers' experiences of information-sharing at a time when they were, perhaps, struggling with impending changes in their lives and starting to think about the need for respite care. There was a sense of them acknowledging that things could not go on as before but

feeling uncertain about the best way forward. For most carers, reaching this point came at a time when they were well-established in caring roles; help-seeking had not taken place at the start of their caring journeys because respite care did not seem relevant to their needs.

Barriers and facilitators

Carers offered various explanations for delaying seeking help from services, including: embarrassment, not knowing where to go for help and apprehension about handing over care.

When they eventually did seek help, most carers relied heavily on informal sources of advice and information about respite services, such as personal recommendations, from family and friends. Over half of the carers attended support groups; these carers identified organisers and other carers as key information sources in relation to respite care options. Nevertheless, for many carers, lack of opportunities to discuss eligibility and access with health and social care professionals typically delayed uptake of respite care. Three carers (all retired health professionals) suggested that, despite ongoing contacts with professionals, health and social care felt fragmented:

‘There is nobody who sort of says, right, you should be handing over [care]. And I honestly think it's too late when it happens (June, C14).

Having shared information with services about the type of respite care that would best suit their needs, carers were disappointed and frustrated when their expectations of accessible and equitable services could not be accommodated. Those living in rural locations, in particular, found that they had little choice in terms of location and types of respite care available to them. Three carers also highlighted that the respite care offered to

them did not really 'fit' the needs of their 'younger' older person. For some carers, a lack of transparency around decisions contributed to feelings of frustration and helplessness. One carer made the point that a change in culture was required:

They're still saying, 'We'll give you'. I'm sorry, dear, but you won't give me anything. You'll provide me with a service I'm entitled to. It's not within your remit to 'gift' (David, C6).

None of the carers spontaneously identified that carer assessments had been undertaken; their perceptions were that respite staff were primarily concerned with the needs of the older person rather than support for carers. This approach from services was generally accepted by carers; after all, they explained, ensuring that the older person would be well looked after was also their chief concern. Several carers explained that they had to be quite assertive to make health and social care professionals understand the need for respite from their perspective:

Eventually I said, 'Do I have no rights? If he doesn't go to the day centre, I've got him twenty-four hours a day and I can't have a break!' (Hester, C9).

Carers maintained that this situation was less likely to arise when health and social care professionals had good understanding of the impacts of caring on relationships and family life. With this in mind, several carers noted the importance of having someone, such as a care manager or support worker, to advocate for them.

Modes of information-sharing

Carers talked enthusiastically about the value of planned ‘admission’ procedures. Visits to services before respite care began, facilitated by service managers/co-ordinators, typically involved collation of key information about the older person as well as discussions about how the service functioned. It allowed carers to get a sense of the place and who would be looking after the older person:

As soon as you go in [residential respite] there are several things that strike you. It smells fresh... everybody seems to be smiling... there's lots of activity and hubbub. I noticed that immediately and thought to myself, 'This holds a lot of promise' (Cathy, C20).

A few carers recalled receiving a telephone call, rather than sitting down with a service manager, to share information about the older person before respite began; this was most often related to in-home respite. In some instances, the caller would provide supplementary written information about the service by sharing a leaflet or website; although this was typically welcomed by carers, at times this approach had its limitations:

See there's their brochure, now it wasn't like that at all! (Colin, C15).

When opportunities for sharing information in an organised and inclusive way were limited, carers' satisfaction with respite was typically undermined. For example, eight carers reported that their first contact with respite services had been as a result of a crisis in their lives; examples included a kitchen fire and a carer having a ‘breakdown’. In contrast, having opportunities to share with staff how they managed at home reassured carers; they were often impressed by the attention paid to detail:

They sat down and asked you everything and filled in a form [residential respite]. What she liked to eat, when she went to bed and about her medications (Bert, C8).

Use of ICTs

Most carers did not use the internet to access information about respite services. There was, however, some suggestion that younger carers, and those who had used technologies as part of their working lives, were more comfortable with using the internet to obtain information about eligibility and access to respite services. In addition, a few carers described using the internet to access Care Commission reports about specific residential respite facilities, as a means of exerting some control over care decisions.

Whilst accessing respite services was rarely straightforward, carers were typically relieved when the time eventually came to try out respite services; for many carers, however, there was also apprehension and guilt related to handing over care to a third party.

Trying it out

The second phase related to carers' experiences of information-sharing amidst the disruption of trying out a new way of 'being'; it was a time of trial-and-error as carers, older people and services negotiated, and sometimes renegotiated, new care arrangements. When perceived shortfalls in care arose, it was often the way that grievances were dealt with that influenced whether carers continued to utilise a service.

Barriers and facilitators

Carers wanted co-ordinated approaches from services where information was shared appropriately and timeously. For example, two carers (both retired health professionals) reported enjoying access to various therapies via the day centre that the older person attended; both noted that a more proactive approach from services would be welcomed by carers:

There isn't a service where someone says, 'Right, you understand what is available to you? You can go to that carers meeting but what else are you going to do?' (June, C14).

Several carers made the point that standards of care hinged on staff being 'led from top' and 'led by example', citing service managers as key people in promoting proactive, solution-focused conversations. When carers' expectations were not met, carers became apprehensive and frustrated. For example, David described how vulnerable he felt when things changed just before he was due to go on holiday; this situation had arisen because information about his wife's care needs had not been updated in a timely way:

I got a 'phone call from the social worker saying that the care home that she'd been in couldn't take her, she'd go to a different one. I balked at that because she liked the first care home... why change it? (David, C6).

Having the time and space to develop mutual understandings often appeared to hinge on carers having the requisite confidence, determination and opportunity to speak to services. Nearly all of the carers described attending or telephoning services in order to address concerns about care (most frequently medication or safety issues). Carers were particularly aggrieved when respite staff appeared to be ignoring information that they had shared with the service:

In the beginning there were little teething problems where a couple of people [respite care staff], we didn't want them back because of some issues [in-home respite] but that was ironed out [via service manager] and we got there in the end (Denise, C17).

Carers who felt unable to speak up about what they needed from services were at a potential disadvantage. Notably, two carers who were experiencing difficulties with transport arrangements withdrew from day centre respite because the stresses of day-to-day arrangements outweighed the perceived benefits; they did not want to be perceived as being ungrateful or petty. Those who reported fewer problems in securing a thorough assessment of their specific needs tended to have worked within health or social care or to have held positions of authority in their working lives. Hester's experiences illustrated that, with negotiation, services were often willing to work in a flexible way that benefited everyone:

Sometimes he'll not get out of bed so I 'phone them [day centre] and say, 'Look there's no point in coming [to pick him up in minibus] and they always say, when he gets up 'phone us and we'll come up for him later (Hester, C9).

Modes of information-sharing

Regular face-to-face contacts and reviews were key to the developing mutual understandings between carers, older people and respite staff. Those who were utilising respite care from a number of different services were more likely to have the support of a care manager to co-ordinate their care package. Several carers commented that over time these meetings became less intimidating because they knew what to expect and who would be present. Carers seemed to especially appreciate when efforts were made to involve the older person in discussions:

Our key worker takes her time and that just suits Alex down to the ground. He's given time to process what's being said and think about what he wants to answer, and she always [carer's emphasis] includes him in whatever she has to say (Cathy, C20).

Several carers who had utilised the 'Getting to know me' tool (Alzheimer Scotland & Scottish Government 2013) highlighted the advantages of having accessible, structured tools to facilitate information-sharing with respite services (as well as other professionals) but recognised the challenges of making sure that what was written down was actioned:

Isobel - If it's there in black and white and people don't read it, it's their fault (C1/3)

Jean - It could almost be seen as a contract between you and the respite team (C1/2)

*Aileen - If it's not transferred to the care plan and that is often where it [the system] falls down, you get staff [residential respite] that aren't normally there, you get new young staff and people are too busy to read and it's just poor communication, 'not getting to know me'!
(C1/4) (Focus group)*

Establishing agreement with respite staff about 'what I need you to contact me about', via timely telephone calls, was identified by carers as crucial, as was being able to trust that the staff would act accordingly. Carers were typically very angry when something untoward happened and they were not informed of the incident in a timely and open manner:

She had her bed socks on this particular night and she fell. I mean, they were full of apologies but we had said to them, 'Do not put these bed socks on. We didn't let her go back (Jean, C1/2).

Use of ICTs

For all of the carers, mobile phones to ‘stay in touch’ during episodes of respite care were indispensable. As carers became more confident about temporarily handing over care, regular telephone contacts with services usually became less frequent. Additionally, some carers (chiefly those who were comfortable with technologies) suggested that paperless information-sharing systems should be utilised to streamline the volume of paperwork they had to contend with and to trial electronic versions of tools such as ‘Getting to know me’.

Despite the challenges that carers encountered when trying services out, most carers described a gradual realisation that their lives could change for the better with input from respite services.

Settled in

The final phase related to carers’ experiences of information-sharing with respite services after shared expectations had been established and all parties had adjusted to doing things in a new way. With the benefit of hindsight, carers offered advice to others about working in partnership with services and highlighted that respite had given them strength to keep on caring.

Barriers and facilitators

Having continuity of staff was regarded as crucial – it influenced the level of personal information shared and types of relationships that developed between carers, older people and respite staff. It also helped respite staff to personalise care (for example, in terms of activities and outings). For Hilary and her husband, this brought some normality to life and enabled respite staff to get to know them as a couple:

There were days when I felt I'd really like to be out with my husband but I couldn't manage myself but Laura [in-home respite] was able to come too! So we would go to the garden centre... I had time to look at the plants and then we had our cup of tea together (Hilary, C18).

For many carers, good interpersonal relationships were pivotal to them having enough confidence to go on holiday, return to work or college, get a good night's sleep and start looking after their own health. Indeed, a few carers confessed that they looked forward to visits from respite staff with whom they had developed particularly helpful working relationships – for them, routine visits had brought unanticipated benefits such as someone else to talk to on a regular basis and opportunities to seek reassurance about the older person's health and wellbeing. It was also important to carers, particularly within the context of in-home respite, that there was a good 'fit' between the older person and respite staff:

As soon as Lynn [in-home respite] comes in, Jimmy [husband] is fine. They'll talk about football... watch TV... they've worked up a good relationship (Grace, C13).

Carers were invariably disappointed when something happened which meant that these connections were lost. For example, 'rules' around eligibility for services meant that sometimes the older person had to change services as their health deteriorated. Moves were easier when co-

ordinated approaches from services were in place (e.g. same key worker looking after the older person within a different part of the service).

Despite routines being established, the risk of respite care arrangements changing were never far from carers' minds:

I am happy with the care package at the moment, although it didn't happen overnight and I had to get seriously crabbit more than once.

And occasionally I still have to get crabbit to make sure we hold on to what we've got (Bert, C8).

Modes of information-sharing

Once care arrangements were well-established, most carers were quite happy to use flexible contacts (not necessarily face-to-face) to address any queries they had or share additional information with respite services. For example, carers might phone or call into the residential respite service, without prior arrangement, to speak to the key worker or service manager. Some in-home and day centre services used a care plan type system, where carer and respite staff would log comments for the other to see and respond to; this worked best when there was continuity of staff:

There was hardly any turnover of staff, they had all been there for years... they worked together, from the guy that drove the bus to the guy that cut the grass (David, C6).

Over time, most carers only wanted to be contacted, by timely phone calls, by respite staff during respite episodes if the older person became acutely unwell or had an accident. Carers frequently made the point that it was not that they were indifferent about more routine things; rather, they recognised the need for a break from their caring responsibilities when they had the opportunity. Nevertheless, regular reviews were still welcomed by carers, with many of them commenting on how useful reviews were in terms of ensuring all parties were mindful to changes in older

peoples' and carers' health and wellbeing, as well as providing opportunities to reassess care arrangements. For example, a few carers described receiving written summaries following residential respite or being invited to attend 'discharge' meetings:

The meeting at the end of the week is very good... we sat around a table and went over things they'd noticed and Mum could be as involved if she wanted (Aileen, C1/4).

Use of ICTs

Once routines had been established, a few carers described coming to personal arrangements with regular in-home respite staff whereby they used mobile phones to stay in touch:

I don't bombard them with texts though. I'm not that kind of hassling person but it's a really good thing, we can keep up-to-date and I feel comfortable knowing I can do that (Denise, C17).

About half of the carers were already familiar with tablets; a few of them spoke enthusiastically about the potential benefits of using technologies to share information during respite episodes (e.g. Skype and audio-visual diaries), however, they thought this might work best once routines had been established:

There should be an opportunity to Skype with my wife. It would reassure her, give me a great deal of confidence... you don't need one in every bedroom, just one in every care home (Jim, C2).

Discussion

There are significant continuities in barriers and facilitators to information-sharing identified within this exploratory study and other empirical studies. For example, in relation to carers' reliance on informal sources for advice and information about respite services (Turnpenny and Beadle-Brown 2014); carers' frustrations when services did not meet their expectations (Shaw *et al.* 2009, Greenwood *et al.* 2012); apprehension about handing over care (Forbes 2012, Phillipson *et al.* 2014); and the risks associated with information-sharing being hurried or based on standardised communications (Payne 2002, McPherson *et al.* 2014, Wilson *et al.* 2015). The multiple accounts elicited from carers taking part in our study, however, identified how barriers and facilitators to information-sharing with respite services changed over time. In doing so, our findings raise fundamental questions about how support for carers is conceptualised and responded to by health and social care professionals, and how carers' preferences can be incorporated within assessment and review processes.

For example, although carers in our study, irrespective of where they lived or socioeconomic background, were regularly involved in assessment processes related to older people, carers were much less likely to receive a carer assessment in their own right. There was also little evidence of anticipatory care being provided for carers within our study; the exceptions being a new local, flexible, personalised short-breaks service and some limited opportunities to access various therapies via local day centres. This is consistent with recent studies which comment on the 'ambiguous position' of carers as 'co-workers' or 'co-clients' (Seddon and Robinson 2014, Glendinning *et al.* 2015). Our study, in line with Moriarty *et al.*

(2015), identifies that health and social care professionals, including respite staff, need to be more proactive in their contacts with carers, not just initially but on an ongoing basis, using different approaches depending on who is being approached, when and why.

Over a decade ago, Nolan *et al.* (2006) developed the ‘Senses Framework’ as a means of giving therapeutic direction for those working with frail and vulnerable older adults. This empirical tool encourages detailed consideration of how staff can ensure that older people, and family members, experience ‘senses’ of security, continuity, belonging, purpose, achievement and significance. There may be merit in using the ‘senses’ as a means of fostering relational aspects of care (between carers, older people and respite services) across the three temporal phases identified within our study. For example, a sense of security seemed particularly important to carers in our study – at first this need for security was related to getting help from a trusted source to find appropriate respite care; this shifted to getting a sense that the older person would be kept safe from harm and have their physical, psychological and social needs addressed; subsequently, carers sought security in terms of holding on to staff and services that they had come to trust and rely on.

In addition, our study indicated that each phase of the caring journey impacted on the modes of information-sharing that were available to, and worked best for, carers as well as on carers’ perceptions of how ICTs could be utilised to support information-sharing between carers, older people and respite staff. For example, once routines were established, carers became more confident about using a service and traditional information ‘transfer’ approaches (such as, face-to-face contacts) became less important; carers subsequently became more open to innovative approaches to

information-sharing with respite staff (such as, texts and Skype). Nevertheless, this was not the case for all of our participants; a third of the carers proffered a resounding “no” when asked about the prospects of ICTs improving information-sharing. This does not, of course, mean that innovative approaches should not be offered to older carers; more that emphasis needs to be on offering choice and being sensitive to changing contexts of care (Dickinson and Hill 2007, Scottish Government 2011b, Sayago *et al.* 2013).

Implications for clinical practice

Our study offers insights, from carers’ perspectives, into what respite staff can do at different phases of carers’ involvement with respite services to improve information-sharing. For example, carers said that opportunities to visit a service before respite care begins are valuable in terms of reassuring carers and older people about what will happen during respite care; and, as new care arrangements are navigated, carers highlighted that regular face-to-face contacts and reviews are welcomed as a means of building confidence and mutual understandings. These insights into what works well for carers should encourage a more proactive approach to respite care provision and direct respite staff to be mindful to the need for ongoing assessment and review. For example, carers who had been successfully utilising respite services for some time appealed for recognition that their needs for support are long-term and that, without firm plans in place for ongoing respite, they feel insecure and disadvantaged.

Our study also emphasizes that use of ICTs to facilitate information-sharing is not necessarily limited by age; from carers’ narrations, the acceptability of innovative approaches to sharing information seemed to be more related to familiarity and accessibility. With this in mind, it seems

timely to explore how texting is being used by carers and respite staff, in what circumstances and whether establishing formal guidelines would be sensible. In addition, whilst some carers chose not to use technology themselves, they often expect ICTs to be used by health and social care professionals to expedite communications about respite care – in terms of establishing realistic expectations, respite services should be explicit about what modes of information-sharing are currently available.

Limitations

There may be limits on how far the findings from this regional study can be transferred to other settings:

- methodological limitations can be seen in the sampling approach, with potential self-selection bias, and the unplanned diversity of data generation methods;
- efficacy, effectiveness or quality of information-sharing processes were not considered;
- and, the perspectives of older people or respite staff were not incorporated.

The study was, nevertheless, valuable given increased policy emphasis on supporting carers and on using e-health to facilitate delivery of health and social care. Moreover, at present there is a dearth of empirical studies relating to information-sharing between carers and respite staff. The issues raised are likely to be of interest to national and international audiences.

Conclusion

Respite services need to work with carers throughout different temporal phases of their caring journeys in a way that responds to carers', and older people's, changing needs. There is some evidence that technology has the potential to enhance information-sharing, by making communications between carers and respite services more timely and person-centred. In some contexts, respite staff are also using technology to communicate via carers' preferred modes of communication. However, for the carers in our study, innovative approaches to information-sharing were considered unlikely to replace the need for traditional information 'transfer' approaches; that is, face-to-face meetings with respite staff, and the investment of time and effort in establishing meaningful relationships with carers and older people, were consistently highlighted as pre-requisites for effective information-sharing.

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Table 1. Sampling frame			
	Generic	Condition-specific	Total
Carers' groups	8	7	15
Community groups	7	8	15
Total	15	15	30

Table 2. Types of respite care	
Type of respite care	Description
Residential	When the older person stays in specifically licensed residential facilities for one night or more.
Day centre	When the older person attends a service during business hours.
In-home	When staff come to the older person's home to provide temporary care.
One-to-one	When a flexible approach to providing care is utilized, allowing the older person to be accompanied by staff to, for example, a support group or social event.
Host family	When the older person stays temporarily with a family (not blood-related) in their home.

Table 3: Sample characteristics										
Code	Pseudonym	Location	SMID 2012 Rank*	Gender	Age of carer	Duration of caring	Caring for whom	Age of older person	Older person's impairment	Types of respite care accessed
C1/1	Maureen	Rural	4	F	50-64	11	Mother	>75	Cognitive	Residential & in-home
C1/2	Jean	Urban	2	F	50-64	15	Mother	>75	Cognitive	Residential & day centre
C1/3	Isobel	Rural	5	F	≥75	4	Husband	>75	Cognitive	Residential & day centre
C1/4	Aileen	Urban	5	F	65-74	6	Mother	>75	Cognitive	Residential & day centre
C2	Jim	Urban	4	M	≥75	1	Wife	>75	Dysphasia	Residential
C3	Bob	Urban	5	M	>75	17	Wife	>75	Visual and auditory	Residential, day centre & in-home
C4	Jenny	Urban	5	F	65-74	7	Mother-in-law	>75	Visual and auditory	In-home
C5	Mavis	Urban	5	F	65-74	5	Husband	>75	Dysphasia	Residential
C6	David	Rural	5	M	65-74	4	Wife	65-74	Cognitive	Residential, day centre & in-home
C7	Ann	Rural	2	F	65-74	20	Husband	≥75	Cognitive	Day centre
C8	Bert	Urban	2	M	≥75	23	Wife	65-74	Cognitive	Residential, day centre & in-home
C9	Hester	Urban	1	F	≥75	5	Husband	≥75	Cognitive	Residential & day centre
C10	Lesley	Rural	4	F	<50	2	Mother	65-74	Cognitive	Residential

Table 3: Sample characteristics										
Code	Pseudonym	Location	SMID 2012 Rank*	Gender	Age of carer	Duration of caring	Caring for whom	Age of older person	Older person's impairment	Types of respite care accessed
C11	Eric	Urban	2	M	65-74	2	Wife	65-74	Cognitive	Residential, day centre, in-home & one-to-one
C12	Sheena	Urban	4	F	50-64	3	Mother	>75	Cognitive	Residential, day centre & in-home
C13	Grace	Urban	2	F	65-74	2	Husband	65-74	Cognitive	Residential, day centre & in-home
C14	June	Urban	5	F	50-64	15	Husband	50-64	Dysphasia	In-home, residential and day centre
C15	Colin	Urban	2	M	65-74	4	Wife	65-74	Cognitive	Residential, day centre, in-home & one-to-one
C16/1	Sheila	Urban	4	F	65-74	10	Mother	≥75	Dysphasia	In-home
C16/2	Tom		4	M	65-74		Mother-in-law			
C17	Denise	Urban	1	F	<50	11	Mother	65-74	Cognitive	In-home
C18	Hilary	Rural	4	F	50-64	6	Husband	≥75	Aphasia	In-home & day centre
C19	Edna	Rural	5	F	≥75	3	Husband	≥75	Cognitive	Residential, day centre & one-to-one
C20	Cathy	Rural	2	F	≥75	2	Husband	≥75	Cognitive	Residential, day centre & one-to-one

- SMID = Scottish Index of Multiple Deprivation

Table 4: Summary of thematic analysis			
Description of phase	Reaching a point	Trying it out	Settled in
Carers' experiences of information-sharing with respite services...	... at a time when they were, perhaps, struggling with impending changes in their lives; acknowledging that things could not go on as before but uncertain about the best way forward.	... amidst the disruption of trying out a new way of 'being'; a time of trial and error as the carer, older person and service negotiate new care arrangements.	... after shared expectations have been established and everyone has adjusted to doing things in a new way.
What are the barriers... ... and facilitators to sharing information?	<ul style="list-style-type: none"> • Insufficient information about services from health and social care professionals • Lack of clarity about eligibility for services • No carer assessment • Lack of insight into impact of caring • Advice and information (personal and professional recommendation) • Accessible and equitable services • Carer assessments • Good understanding of the impacts of caring 	<ul style="list-style-type: none"> • Lack of co-ordination between services • Intimidating, service-centred case conference meetings • Respite care staff who ignore carers' expertise • Inflexible service delivery • Co-ordinated approaches from services • Proactive, solution-focused conversations • Time and space to develop mutual understandings • Flexible orientation from services 	<ul style="list-style-type: none"> • Lack of continuity • Unsatisfactory interpersonal relationships • Changes in service delivery (personnel or venue) • Co-ordinated approaches from services • Continuity of staff • Good interpersonal relationships
What modes of information-sharing work best for carers?	<ul style="list-style-type: none"> • Planned 'admissions' procedures • Supplementary written information (leaflets/ websites) • Organised and inclusive approaches 	<ul style="list-style-type: none"> • Regular face-to-face contacts and reviews • Accessible, structured tools • Timely telephone calls 	<ul style="list-style-type: none"> • Flexible contacts (not necessarily face-to-face) • Regular reviews • Timely telephone calls
How might ICTs be utilised?	<ul style="list-style-type: none"> • Internet to publicise information about eligibility and access • Internet to share Care Commission reports 	<ul style="list-style-type: none"> • Mobile phones to stay in touch • Paperless information-sharing systems, such as electronic version of 'Getting to know me' 	<ul style="list-style-type: none"> • Mobile phones to stay in touch • Skype/ audio-visual diaries to share information during respite episodes