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Understanding factors influencing residential respite service use by carers of people living with dementia using Andersen's behavioural model of health services use: a qualitative study

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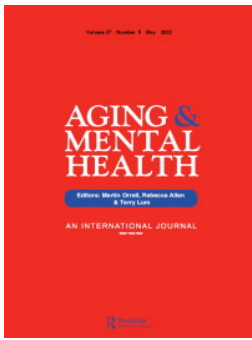
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Understanding factors influencing residential respite service use by carers of people living with dementia using Andersen's behavioural model of health services use: A qualitative study

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ABSTRACT

Objectives: Residential respite (RR) provides a valuable break for family carers, but little known about its offer, take-up or experiences of carers of people living with dementia. This paper aims to further understandings of factors influencing RR use.

Design: RR stakeholder workshop and qualitative interviews.

Setting: Stakeholder or living in the community in own home.

Participants: RR stakeholders (13); family carers with experience of RR, or had declined it, or were planning to use it for the first time ($n = 36$).

Methods: Stakeholders participated in a workshop to discuss provision, models and funding of RR. Family carer interviews focused on expectations, experiences and outcomes of use of RR. Data were analysed thematically and mapped against Andersen's model of health service use.

Results: Identifying need for RR does not necessarily transpire into use. Planning and ease of booking were crucial for carers, but many felt there was little support with this. Systemic factors concerning funding, planning and booking RR act as barriers to its use.

Conclusion: Findings highlight how systemic factors influence RR use. Discussing respite need in routine care planning or reviews may support carers and people living with dementia to consider RR, but system changes are needed to address barriers.

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dementia; qualitative research; care home; respite; carer; health behaviour

Introduction

Residential respite (RR) for people living with dementia is a short stay in a care home with the aims of providing carers with a break from caregiving and offering care recipients a break too. It is often reported as enabling carers to support their relative at home for longer (O'Shea et al., 2019).

We currently know little about how RR is offered, taken up or viewed by people living with dementia and carers. In England, Alzheimer's Society (2020a) aptly labelled the experience of carers as working through the 'fog of support'; evidenced in carers' accounts of how they had 1) sought to identify appropriate support and respite options for their relative living with dementia, 2) tried to access or take up acceptable options, and 3) received little information about services, entitlements and possible benefits (ibid.).

Respite is a frequently expressed need of carers; however, respite services are often underutilised (Leocadie et al., 2018). This research suggests that this could be because of stigma and therefore reluctance among carers towards accepting help, or that existing respite services may not be satisfying carers' specific needs. Respite services can also vary, in terms of whether it is offered during the day or night, for a short or longer period of time, whether it is at home, at a day centre or in a care home (Gottlieb & Johnson, 2000). When it works well, respite can have myriad benefits, such as decreasing loneliness, anxiety and depression, improvement in family relationships

and some longer-term benefits to carer health (Leocadie et al., 2018).

There is enormous diversity of understandings of the respite experience. Some of the factors may be: who is involved, nature of the respite service, characteristics of carers and their relative living with dementia, their relationship, living arrangements, socioeconomic status, level of disability, other sources of support—and, indeed, the type of research conducted to understand it (Neville et al., 2015).

Andersen's model (Andersen, 1995) aimed to understand why and how people use health services, and enabling factors and predisposing factors that guide people towards the determination of need. It comprises three underlying constructs: predisposing factors at an individual level (socio-demographic characteristics, and beliefs and attitudes), enabling factors at a service level (availability of resources to access care), and need factors (evaluated and perceived).

The model has been used to increase understanding of respite services in reviews (Childers, 2019), as well as empirical research on long-term care use and day respite services (Savard et al., 2009; Brown et al., 2014).

This paper presents findings from a two-year study funded by Alzheimer's Society which explored the expectations, access pathways, and outcomes of RR for people living with dementia and their carers. Using the framework of Andersen's Behavioural Model of Health Services Use (Andersen, 1995; Travers et al.,

2020), subsequently adapted to understand long-term care use (Bradley et al., 2002), this paper presents factors influencing use of RR.

Methods

Study design

Utilising qualitative methods, our two-part study sought to investigate experiences of access, expectations and outcomes of RR for older people living with dementia and family carers in England.

Part 1 investigated current provision to create a 'map' capturing the diversity of RR provision that was informed by providers, commissioners and users of respite services, and which included contexts of paying for RR. Findings also informed interview materials for Part 2. Part 1 involved a brief mapping exercise of available services, and a workshop held in October 2019 which aimed to learn from RR stakeholders' views of the adequacy of existing models and provision of respite and identify current respite funding sources. We felt a workshop would give stakeholders a chance to discuss and debate some of these issues rather than state them via a 1:1 interview.

Part 2 interviewed people living with dementia and carers between March 2020 and December 2020. We also interviewed seven people living with dementia. Their interviews focused more on the experiences of using RR, and many did not discuss contributing to the planning and organising of respite.

Recruitment

We recruited stakeholders for Part 1 using networks and research and service contacts. We also issued a call on social media outlets and through wider care home networks encouraging practitioners working in RR services for older people living with dementia to get in touch.

For Part 2, we recruited family carers (aged ≥ 18) of older people living at home with dementia from three categories of interest to the study: those with experiences of RR, those who had declined RR, and those planning to access RR. We aimed for a diverse sample (ethnicity, gender, age, relationship type) to gain a breadth of knowledge and experiences. We registered the study on the Join Dementia Research network and advertised the study widely amongst our networks, via social media, and publicity through local and national voluntary groups and care home networks. We used principles of data saturation to determine the point at which no new information was forthcoming.

Data collection

At the stakeholder workshop views on RR were gathered using a set of pre-determined discussion points, broadly focusing on adequacy of existing models of respite, covering care homes and other models of short breaks (see Box 1 for the full list). Ninety minutes of the three-hour workshop were dedicated to this discussion. The research team facilitated the workshop and took notes in breakout groups, comprising 4 to 5 members each (randomly allocated), which were later discussed as a whole group.

For Part 2, two researchers undertook single interviews with participants at mutually convenient times, via telephone and

Box 1. Questions discussed at stakeholder workshop

- a. What do you think are the pros or cons within the current RR care models available?
- b. Do you know of any other innovative models that can provide a break to carers of people with dementia?
 1. What can Local Authorities do in terms of market shaping (as they are responsible for this under Care Act 2014)?
 2. If you were to design your ideal respite service, what would you include?
 3. Do staff working in services that provide RR need different skills than long-stay care home provider staff? if yes, what would these be?
 4. What, if anything, is the role of RR in the dementia pathway?
 5. What is the role for dementia navigators and other similar roles in talking about RR?

video-call applications (apps), and audio-recorded interviews with permission. Interviews lasted approximately 45 min, and included questions about participants' experiences of RR, how/ if they had accessed it, what outcomes of RR had been, if any, and what might have been helpful to know before or during their RR stay. Participants' demographic information was also recorded.

Ethical considerations

Ethical approval for the study was granted by King's College London's (KCL) SSDL Research Ethics Subcommittee in August 2019 (ref HR-18/19-10641) for Part 2 of the study. Part 1 did not require ethical review as it included professional stakeholder views and did not aim to produce generalisable or transferable findings; stakeholders consented to anonymised quotation of their words. We reassured participants of confidentiality and anonymity, informing them of rights to withdraw or terminate interviews. Processes of informed audio-recorded consent were undertaken before proceeding with interviews since postal services were affected by the Covid-19 pandemic. Interviewers were alert to the possibility of distress and planned to offer to stop or pause the interview should the participant appear uncomfortable. A safeguarding protocol was in place should we hear about or witness possible harm, and a 'contact sheet' of helpful resources was offered to participants. In reporting, we have assigned participant numbers to retain anonymity.

Data analysis

Notes from Part 1 were written up and collated. Audio interview recordings in Part 2 were transcribed verbatim. All textual data were analysed using principles of reflexive thematic analysis (Braun & Clarke, 2021), with a focus on broad and cross-cutting themes or trends.

A random set of participant transcripts was coded line-by-line by three researchers, and a broad coding framework focusing on descriptive themes developed. This, and any divergent views, were discussed within the study team and a final coding framework was applied to all data. This was also applied to the stakeholder workshop notes. As the relevance of identified codes to Andersen's model of health service use was noted, we mapped all the codes against the model to understand respite use and where gaps in provision and service uptake may lie. Analytical process was clearly documented in a rigorous paper trail via notes and memos to ensure authenticity and demonstrate rigour. The research team was female, with backgrounds in gerontology, health and care research, psychology, caregiving, and

care home governance, each with over 10 years' experience in dementia and/or social care research. Through bracketing, we acknowledged and separated our knowledge of literature to remain authentic to participants' accounts. By presenting evolving findings to the study's advisory group (comprising care home providers, social care and dementia experts, and people affected by dementia) in an online meeting, we obtained additional reflections and insights. We have adhered to the Standards for Reporting Qualitative Research (O'Brien et al., 2014) to demonstrate transparency, authenticity and credibility.

We were guided by principles of rigour and trustworthiness in qualitative research (Williams et al. 2020): applying credibility and transferability (thick description of study context and individual participant characteristics), aiming for authenticity and transparency in reporting (clear paper trail), and engaging in researcher reflexivity (thoughtful description of research team and considering the various strengths and limits of each member).

Findings

Participant characteristics

The stakeholder group comprised 12 members: RR providers, a representative from a large dementia-focussed charity, a dementia trainer, carers' group representatives and advisors, family carers, and dementia researchers. One stakeholder, unable to attend, contributed via a separate interview; their views are included into the group's data. Most (9) were from London and South-East England.

We interviewed 36 carers (2 carers were jointly caring for a relative; 4 were former carers): 31 women and five men, age range 30–83 years, living in six English regions. Thirty were White British and 6 Asian or Black. There were equal numbers of adult children and spouse/partner carers. All but two reported being heterosexual, and 31 participants lived in owner-occupied homes, the majority housing tenure in England (See Table 1). All interviews were conducted in English.

Mapping onto Andersen's model

Analysis and themes were mapped onto the three salient constructs of the Andersen model: (1) enabling factors at service level (availability of resources to access care) (2) predisposing factors at individual level (socio-demographic characteristics, and beliefs and attitudes), (3) determination of need. We further extrapolated more closely the influence of system-level processes of planning and booking respite to understand the gap between determining a need for respite and its use. We report this as the fourth construct influencing RR use. Figure 1 is a graphical representation of this model; and Table 2 contains a summary of analytical categories, themes and subthemes.

Enabling factors

Enabling factors to determine need were those at a service level, and included (1a) 'Stumbling in the dark', (1b) well-timed nudge and (1c) the role of market shaping and regulation from the perspective of stakeholders.

'Stumbling in the dark'

Carers described the process of arranging RR as extremely complicated, and any assistance seemed to them unspecific and

Table 1. Characteristics of carers interviewed (35 interviews, 36 participants*).

	TOTAL
Gender:	
Female	31
Male	5
Age range (in years):	30-83
0-29	0
30-39	1
40-49	2
50-59	9
60-69	12
70-79	9
80-89	2
Missing	1
Ethnicity:	
White	30
Asian	4
Indian	2
British	2
Black	2
Caribbean	2
Relationship:	
Spouse / partner	16
Parent	15
Sibling	1
Other family member	4
Sexuality	
Heterosexual	34
Gay/lesbian	1
Bisexual	1
Housing Type	
Owner occupied	31
Rented privately	2
Rented Local Authority/Housing Association	3

*Two carers, caring for the same person, participated in one interview.

impersonal. Complications reported included whether and when to decide on respite care, finding a suitable home, and ways to go about arranging the break. Two sub-themes contributed to this experience: access to timely information and the impact of a social network.

Access to appropriate and timely information

Accessing accurate information at the right time in order to consider a respite break was difficult, and carers considered information given to them was out-of-date or irrelevant. Often social workers simply provided a list of local care homes to choose from, and suggested carers look at websites and go through Care Quality Commission (the regulator) reports themselves. Many carers felt this was impersonal, unspecific and unhelpful; and that the responsibility of providing carers with appropriate information was shirked by professionals:

I think the outside agencies could do more to help definitely... but then when you say, 'have you got a list of places you can recommend?', 'Well we're not allowed to recommend anything. If you get this booklet or go on this website...', which is passing the buck somewhat. And even, I think, you know, the information that's provided by the local authorities in their booklet and on their websites, it's very limited. It just tells you whether a home will do nursing, dementia, etcetera. Because I mean I was stumbling in the dark a bit to start with. (Carer 009, had experienced respite)

Social networks

Several participants mentioned the value of social networks and personal recommendations in choosing a respite home. Some carers with experience of respite felt that if their relative had a personal connection to the care home this was reassuring, be it friends who recommended the care home, or a past connection to the locality:

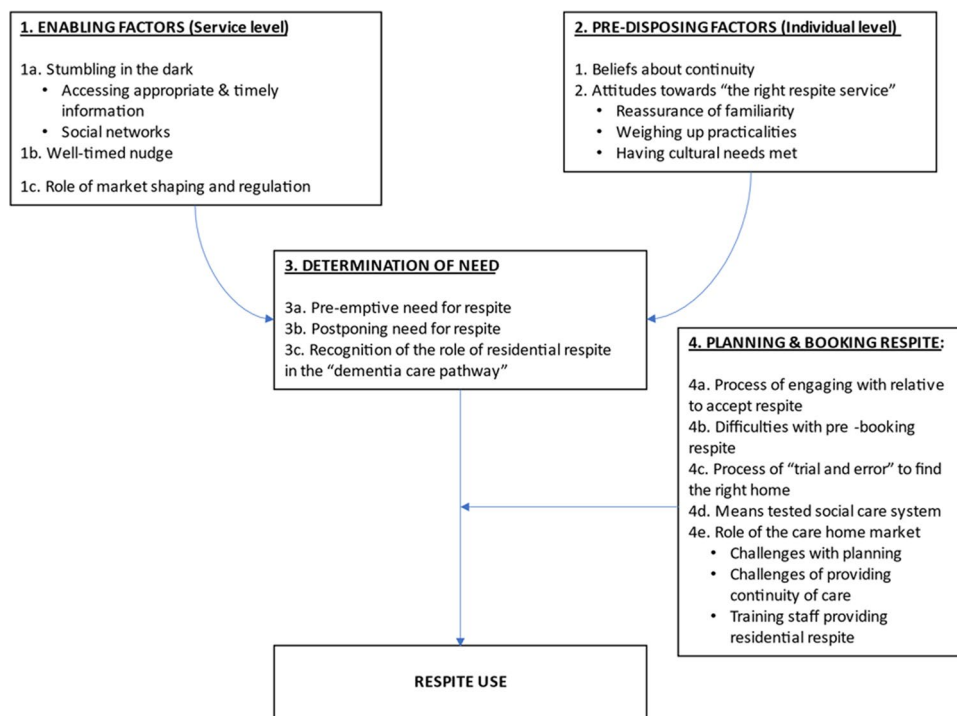


Figure 1. Influences of planning and booking processes on respite use, based on Andersen's Behavioural Model of Health Services Use (Andersen, 1995).

Table 2. Analytical categories, themes and sub-themes.

Category	Theme	Sub-theme
1. ENABLING FACTORS	1a. 'Stumbling in the dark'	1ai. Access to appropriate and timely information 1aii. Social networks
2. PREDISPOSING FACTORS: Individual level	1b. Well-timed nudge	
	1c. Role of market shaping and regulation (2a) Beliefs about continuity 2b. Attitudes towards 'the right respite service'	2bi. Reassurance of familiarity 2bii. Weighing up practicalities 2biii. Having cultural needs met
3. DETERMINATION OF NEED	3a. Pre-emptive need 3b. Postponed need 3c. Recognition of the role of RR in the 'dementia care pathway'	
4. PLANNING AND BOOKING RESPITE	4a. Process of engaging with relative to accept respite 4b. Difficulties with pre-booking respite 4c. Process of trial and error to find the right home 4d. Means tested social care	
	4e. Role of the care home market	4di. Self-funders 4dii. Expensive and impacting uptake 4ei. Challenges with planning for availability 4eii. Challenges of providing continuity of care 4eiii. Training staff providing RR

When you start looking for a care home, you don't know where to start. Personal friends' recommendation is the best way, I think, of going about it. And with that one, that was my friend who had said her mum had got on there, she was always very happy there. And then, more recently, beginning of this year, I was looking again for a care home and I've been talking to another different friend of mine who a friend of her, her husband had gone into one locally, more local to me and so I went to visit that one as well this year. (Carer 001, awaiting respite)

Well-timed nudge

A small number of carers described the value of support they received, either from professionals or from family members, who understood their circumstances, personal contexts, and nudged them towards accepting RR. In one case, this nudge was reported to have come from an Admiral Nurse (specialist dementia nurse) who had been visiting the carer and her mother for some months and was therefore able to spot the carer's exhaustion:

Participant: My Admiral Nurse at the time, obviously was visiting me regularly and she kept giving me the opportunity to book a respite break because I needed it. But, in the end, she took it and did it herself because I didn't want to at the time. So that's how I got into it, really. She helped me through the process as well.

Interviewer: Okay, and what do you mean by you didn't want to, and she went ahead anyway. That sounds interesting?

Participant: Well, she made me realise that I needed the break. I was getting to a level where I was struggling a bit. And she realised I needed the break and she spoke to me about it. Obviously I agreed to it, but I wouldn't initiate it myself and start it off because I just felt very guilty about leaving my mum. And, at the time, I just felt that nobody could look after my mum like myself. (Carer 013, had experienced respite)

Role of market shaping and regulation

Stakeholder participants considered that Local Authorities (LAs) could be more active in their 'market shaping' of RR services. Many felt that the rise in requests for emergency RR was a symptom of the lack of early help for carers, resulting in them

reaching breaking point. One suggestion was that LAs should arrange longer-term funding with care homes for respite services or run respite services themselves. A need for personalised information and advice was voiced, as several thought carers often did not know of local respite options, eligibility criteria, and funding options. The group noted that those receiving public funding for their care had more limited respite options than people who met the cost themselves.

Predisposing factors: individual level

Predisposing factors contributing to need were identified at an individual level: (2a) beliefs about continuity, and (2b) attitudes towards 'the right respite service'.

Beliefs about continuity

A prevailing belief of carers who had refused respite was that respite would threaten continuity of care for their relative living with dementia, and be detrimental and unsettling. Participants who had not taken up respite felt their relative benefitted from a consistent routine, including attending local activities and/or meeting neighbourhood friends, so respite would be disruptive:

But you know, there were lots of downsides to [a respite break] as well because it's taken us a long time to get my mum into a routine and she attends lots of different activity groups. And obviously if she were going to stay in a care home for a while, even if it's just a week, that's a disruption to the routine. And with her dementia as it is we just felt it might be too disruptive. She'd lose all that routine, she'd get very confused and then we'd have to almost start from scratch again when she got home to re-establish the routine. (Carer 002, declined respite)

Attitudes towards 'the right respite service'

Those participants interested in respite commented on the importance of choosing the 'right' home so that they could be confident that their relative was being well looked after in their absence.

Reassurance of familiarity

A care home that had some familiarity to the person living with dementia was described as the best option, as this could help counter worries about disruption and distress. Carers described this as less confusing for their relative living with dementia, and being reassuring for them. One participant felt so strongly about a familiar care home that they were willing to forgo a respite break in a different care home:

My preference is the one [my mother] goes to [for previous visits]. If [the care home] come back and say, "no," I would actually prefer to change my holiday because I know that my mum is happy there, and [staff] know my mum, and I know a lot of staff and that there now. I've already seen it. I don't want to be starting from scratch every time mum goes into respite; it's not fair on my mum, for starters. Because she does sort of recognise, because again it was part of her routine, if you like. But if you're going to expect her to adjust to different homes, that isn't fair. And then how are you meant to feel? It's bad enough anyway. I always feel guilty, I always cry. I think you should have a good rapport with the home and get to know the staff and the surroundings and they get to know mum - makes it much nicer than having to deal with different homes all the time. (Carer 013, had experienced respite)

Weighing up practicalities

Carers weighed up many factors when deciding on what constituted the 'right care home', including practicalities such as visitor parking or public transport, as well as identifying care homes where practices of good quality care, keeping their relative socially active and stimulated, and homeliness were evident:

I don't tend to rush into things. And I will need to speak to the care home. In fact, the one that is nearer to me is easier for me to get to because they've got parking; the other one you can't park anywhere near which makes it very difficult. But I would want to know a lot more about how they've actually got on during all this (pandemic) ... (Carer 001, awaiting respite)

Having cultural needs met

For some carers, the right care home was one where individual cultural needs could be met. Elements that contributed to this judgement were food choices, activities offered, and a connection to a place of worship:

But, when she got in there, the thing was is that the place was semi-culturally appropriate if you like. She's a black woman of African Caribbean background. Born in Jamaica and came here in her 40s so, culturally, she took on some of the British culture but, culturally, that was it. So, the home, if you like, if they weren't giving her her Caribbean foods and stuff that would make her damn miserable, you know what I mean, really damn miserable. But they were able to offer some of that, so that was one of the things that we ensured that the home can provide before we said yes to it, which was excellent, which was important. Also, the other thing was that, she was religious and they used to have a church service in the home as well, so those two things were very important. (Carer 014 had experienced respite)

Determination of need

While previous versions of Andersen's model have differentiated need as 'evaluated' and 'perceived', our findings indicate that carers took one of two approaches when determining whether to use respite: (3a) pre-emptive need and (3b) postponed need. A further sub-theme is that of (3c) recognition of the role of RR in the trajectory of dementia care.

Pre-emptive need

Some carers were pre-emptive about identifying a need for a respite break, and made plans for a future break by anticipating when they might need it. For some, this was on the advice of family or friends; others realised themselves that they needed to prevent problems escalating:

Because things are beginning to get a little bit on top of me with my husband [living with dementia]. I've always said that if at any time he doesn't know me or if he gets violent, I won't be able to look after him. But it was getting very difficult looking after him. We were sort of rubbing each other up the wrong way, you know. There was a bit of aggravation. We weren't as happy as we could be. (Carer 001, awaiting respite)

Postponed need

Not all carers were proactively planning for respite. Some potential need for a break was postponed by carers who made

use of other sources of support to get a break; such as calling on other family members, such as another sibling or adult child, to support a parent with dementia. Some participants felt no need to plan for respite when things were stable, on the assumption that relevant support would be available if the need arose:

I do think about it [RR] but it's not on my big agenda because everything's ok at the moment. I know... how things can go from A-Z so quickly and you always think you've got time. You always think you'll get the support... but nobody has made any contact with me about my husband in terms of how we're coping, his dementia... and nobody has made any contact whatsoever... (Carer 007, declined respite)

Recognition of the role of RR in the 'dementia care pathway'

Stakeholders acknowledged how RR is sometimes used as a 'stepping stone' to a permanent care home move. Stakeholders' experiences were that this tends to happen when carers recognise they can no longer cope and it seems best for their relative to move, when a place in the care home becomes available, or when a carer finds that their relative living with dementia enjoys their stay and/or wishes to move to a care home. While most agreed that such 'stepping stones' were common and many RR stays did convert to a full-time permanent move, one member of the group (an ex-carer) felt the opposite was true—that regular breaks enabled her to continue caring at home, and improved relationships. A carers' group advisor at the stakeholder workshop said they encouraged carers to consider RR early, even if they did not feel they needed it, advising them to make a 'mental note' of local care homes for if the need arose. The group debated whether local authority carers' assessments under the Care Act 2014 would accurately identify those that needed residential respite or a break; as many carers may simply dismiss enquiries about themselves with 'I'm fine'. The lack of follow up of these carers' assessments was bemoaned as was the means-tested basis of eligibility for publicly funded social care.

Planning and booking respite

The process of planning and booking respite was seen as problematic to arrange in advance, with not being sure how their relative would engage with respite, and a process of trial and error in finding the 'right home'.

Process of engaging with relative to accept respite

Some carers who had taken up an offer of respite described the process of getting their relative living with dementia 'on board' with this. One carer said their relative, despite accepting it, was perpetually anxious during their respite stay that the move was going to be permanent. Some carers found it helpful to mention that another friend would be there too:

This year [husband] did agree to go. And also the fact that [our friend] that goes to one of our groups who also has Lewy body brain disease, he was going to go in at the same time as my husband. And... one of our groups is held at a residential care home and it's a lovely home and we've got to know the staff. and I wouldn't hesitate having a week's respite, with [our friend] going in there to that particular home. (Carer 002, awaiting respite)

Difficulties with pre-booking respite

Several carers found the care system was not designed for pre-booking respite. One attributed this to changes since Covid-19 which were understandable, while another reported that local care homes tended to have spaces for emergency respite, less so for planned breaks. This carer felt being unable to book in advance in her area made it difficult to plan a holiday or activities during the respite break:

Just one thing more about RR is that many care homes in this area, I don't know if it's across the board, but a lot of them won't do pre bookings; some of them are just emergency care. Whereas the respite unit that mum used to attend... you [used to be able to] pre book it for your holidays. So, how can you plan when you don't know when your loved one's going?... In residential homes, what they do now is I phone Social Services, put the dates in that I want. [Social Services] then pass it over to a team, who then contact the local homes to see if they've got a spare bed for the day that I want. So the reality of that is: I might not get the dates I want, I might not get the home I want. (Carer 013, had experienced respite)

This experience was reflected in stakeholders' accounts. One provider felt that the numbers of carers seeking emergency RR were increasing, and they were unclear about whether this was because carers did not acknowledge the benefit of regular RR, or whether they could not access it. Some felt that emergency RR at a time of crisis was far more distressing for the person living with dementia, and ought to be avoided, if possible, with support put in place for the carer such as extra help at home.

Process of trial and error to find the right home

Finding a suitable care home was for some a process of 'trial and error'. Several carers with experience of RR talked of trying it for a night or two before booking it for a week or more. Some carers had used the same home for several respite breaks for their relative, and mentioned the familiarity as reassuring to both them and their relative. One had used her experience to further personalise the arrangements:

Originally we did Friday to Friday and then I realised it's not a good idea to go in [to a care home] on a Friday because you've got a weekend when there's different staff. And so I then did it Monday to Monday or, quite often, Tuesday to Tuesday so we didn't miss one of our favourite meetings. And so that meant that he had seven nights there. And it went from lunch time on that day to lunch time the next one, and I would stay and have lunch with [relative living with dementia] when he went in, and have lunch with him when I collected him to bring him home (Carer 006, had experienced respite).

Means tested social care

The means-tested basis of English adult social care meant some carers and their relatives met the cost of respite (and other services) themselves (as 'self-funders') while others' costs were met by their LA.

Self-funders

Some self-funders described having greater choice as a result of their purchasing power, and compared themselves to friends who were reliant on LA arrangements and still waiting for the 'right' care home:

I thought it would be really hard to find a place. I'd always heard that respite care was in high demand and very difficult to access. But then, my dad was in a fortunate financial position which is a great shame because not everybody's in the same position as him and I understand that, so it was easier to access than I expected. (Carer 010, had experienced respite)

Expensive and impacting uptake

Nonetheless, many carers found a respite break expensive, thus reducing uptake:

I couldn't afford to do it myself on a regular basis. So, if funding wasn't provided, it would be much more difficult. I mean I could do it maybe on one occasion and if I got desperate enough then I would but, I mean, I haven't got infinite resources, we've got some savings but it's certainly not lavish savings. (Carer 012, had experienced respite)

Role of the care home market

Stakeholders discussed what the role of the care home market in planning for respite ought to be, and they identified three main factors that made planning for respite time-consuming and costly for care home providers.

Challenges with planning for availability

The problem of matching individual need with availability of local respite services was raised by carers' representatives focusing on the unpredictability of needing a break and unpredictable vacancies. Care homes found it hard to keep rooms available for 'respite' as demand was hard to plan for and empty rooms affect revenue. Attached to this was unpredictability of staffing rotas, as some providers mentioned that carers were sometimes reticent (or unable) to accurately report the needs of their relatives with dementia and this placed additional demands on staff if the person had far greater needs than the care home had anticipated.

One care home provider described the regulations underpinning respite in care homes, including minimum requirements for a full care plan in place. They reported having to provide staff for, on average, a 'two-hour pre-admission visit plus an hour to write up a care plan, plus three to four hours for induction (to the individual and family)—and this is before even starting care' (Stakeholder 11). Two other providers referring to the costs of pre-admission work, had established a minimum stay for RR of four weeks to make 'business sense'; one of them also considered that a four-week break was likely to be more restorative and relaxing, and that too short a break could perhaps be more disruptive to the person living with dementia. Many others in the stakeholder group, however, felt that a month-long stay was too costly or generally not possible for most carers or people living with dementia, and therefore this requirement would come across as prohibitive.

Challenges of providing continuity of care

Providers described making judgements about whether a person living with dementia would be a 'right fit' in their care home for a short stay, and expressed caution about disrupting the routines of permanent residents. They did not always refuse a place for someone seeking RR if the 'fit' wasn't 'right', but tried to alleviate any potential distress to permanent residents as a first step. Providers in the stakeholder group also felt that despite substantial pre-admission work, such as a visit before

the break, these early visits were not always sufficient to provide a detailed picture of how a person living with dementia would settle in.

One carer reported that their mother's behaviour (singing) had been so disturbing to the other residents that staff had decided that the needs of the permanent residents mattered more and therefore refused a third respite stay.

... my mum, at the time, was going through a, want-to-sing-out-loud phase. Because my mum does have a lot of phases that she goes through, and, at that time, she was singing literally on a loop; as soon as she was finished, she'd start it again. So, when we went to view [a care home] I did specify this and say, "look she does sing a lot. Is this going to be a problem?" "Oh no," [staff at respite home] said, "we'll embrace that, they'll love it here, get everyone singing." Lovely. Okay. Mum went for the day just to see how it all worked out. Fine. Lovely. She stayed twice and nothing was said about her singing, only that she did sing, it wasn't a problem. I went to book the third holiday or respite week, and they refused her because it upset the [other] residents. (...) Because you're going into somebody else's home, aren't you? (Carer 013, had experienced respite)

A provider from the stakeholder group described their practice of seeking volunteers from among the permanent residents to act as an 'ambassador'. Wearing a badge to indicate this role, they helped greet and settle new residents. This model worked well with new and temporary residents. Many noted that not all carers seeking RR needed a holiday or a break, some could be unwell themselves or need medical treatment.

Training staff providing RR

The need for skilled staff to work with people living with dementia who take up RR was acknowledged by all stakeholders. Staff supporting people staying for respite were thought to need to learn about them very quickly, be hospitable, be able to reassure anxious family carers, and condense care planning without compromising quality. Many felt these skills came with experiences of good practice, and it was difficult to train or prepare for.

Relatedly, views were mixed about whether a 'RR only service' was preferable to a larger care home with RR places. Some felt that a dedicated service may be preferable as staff could gain experience and devote their attention to getting to know these residents quickly, but some felt it would not be viable as demand was too unpredictable. Carers' representatives felt that while this may be beneficial for someone living with milder dementia, for those wishing to try out a period of RR before deciding on a permanent care home move, this option would provide little insight if they wanted to feel what living in a busy, fully occupied, care home would be like. Specific cultural needs would also be harder to cater for in a RR-specific service unless there was a diverse pool of care workers to draw on.

Discussion

Findings from this study indicate that enabling factors and pre-disposing factors influenced two types of need for respite services: pre-emptive and postponed. The premise of this article is, however, on the activities of planning and booking respite and their influences on the gap between need and use. In other words, just because a need for respite was identified by carers, it did not transpire into use for system-related reasons; and we have extrapolated the systemic issue of how planning may prevent potential need from becoming an unmet need.

Our analysis also suggests that Andersen's model of health services use may be relevant and applicable in social care, having been previously used to understand the use of day respite services (Brown et al., 2014; Iecovich & Biderman, 2012). The model's use in the UK context is rare, less so in empirical research, and not with qualitative research to extrapolate each of the constructs of the model from in-depth perspectives of service users and carers.

Enabling and pre-disposing factors

The absence of appropriate and timely information has been identified in post-diagnostic support for people living with dementia and carers (Robinson et al., 2011). Carers would benefit from specific, personalised information rather than simply a list of local care homes, and our findings resonate with the notion that personalised support resulted in more straightforward respite. No statutory service seemed to sufficiently consider individual contexts and needs, and in many cases, a person's social capital of networks and personal recommendations proved valuable. Inability to recognise need or to plan for emergencies may result in carers reaching breaking point or a crisis, and the person living with dementia receiving emergency respite.

At an individual level, several prevailing beliefs and attitudes influenced carers' perception of needing a respite break. Several carers reluctant to use respite cited the disruption of care as the reason for not considering respite, with the worry of an unfamiliar environment, and risks of destabilising routines. Stakeholders also recognised the value of continuity for people living with dementia. Maintaining routine for people living with dementia is generally important (Porock et al., 2015); and there is need for more evidence about how people living with dementia and carers can cope with change and make the best of a short break.

Finding the 'right care home' is important for a permanent move; and our study indicates that the same considerations applied for respite: one that is familiar in some way (Caldwell et al., 2014), conveniently located and practical for visiting (Lord et al., 2016), able to meet specific needs such as cultural preferences (Ashton et al., 2016). All were important for a short stay; but difficult due to limited availability of respite provision and in accessing what there is. As noted by others (O'Shea et al., 2019; Alzheimer's Society, 2020a), those who fund their own care have more options than those reliant on public funding; but even among self-funders anxiety about paying for care could prevail.

Enabling and individual factors resulted in some carers identifying a need for respite to prevent problems escalating or postponing need for a care home move; but some mentioned that other sources of support, such as live-in care, could provide respite at home (Hogan et al., 2022). Some carers were confident that there would be advice available in the future should they need it; while others' experience was that this was greatly over-optimistic.

Planning and booking respite

There were many challenges encountered when planning for respite and making these arrangements, underpinned by systemic problems in how respite care is part of a care market, shaped more by care providers than by LAs or health services.

For individual carers problems lay in different factors needing to align before a RR service could be accessed. If someone's relative living with dementia is generally reluctant or anxious about a respite stay, it may be difficult for their carer to plan a break away or a holiday to coincide with finding the 'right home' at the right time. Difficulties in advance booking often meant that carers were unable to plan a break, nor prepare their relative with any level of certainty. Options were limited and confusing for those who were not self-funding their care, although respite breaks could be expensive for self-funders.

The trial-and-error nature of finding the 'right' care home compounded this situation, especially if a person living with dementia was reluctant to take the break. Care home providers mentioned this was hard for staff to manage but also raised the business challenges of keeping rooms for 'respite' stays only, alongside unpredictability of staffing; so respite arrangements could be time-consuming and staff intensive. Minimum care plan requirements for care homes were sometimes considered onerous and some stakeholders reflected that it only made 'business sense' to offer minimum periods of stay. The need for skilled staff to support short-stay residents and learn of individual preferences was another cost element facing care homes whether for profit or not-for-profit (Barron & West, 2017).

The future of respite care

As the world strives to reset after the worst of the pandemic restrictions, and services aim to rebuild, the need for support for family carers is likely to rise (Alzheimer's Society, 2020b; Tuijt et al., 2021). However, support is multi-faceted and a respite break may not be everyone's wish. Local respite services are variable and often hard to access, with insufficient attention paid to respite in care planning and carers' own assessments. While care homes may need to consider the clarity of information provided about respite services, and ensure it is up-to-date and build confidence in local communities (Samsi et al., 2022), LAs could reflect on their market shaping responsibilities so there is some provision locally, and ensure their own information is accurate and confidence-enhancing. Professionals too may need to be more willing to take the time to discuss attitudes and beliefs about taking breaks with carers and not shy from providing advice as well as information. Previous studies have found that respite can be a stepping-stone to a permanent care home move (Cole et al., 2021; Samsi et al., 2022), depending on whether the person living with dementia enjoyed the stay, whether the care home had a vacant room at an opportune time, and what indeed the respite break had meant for the carer. Recognising this may enable more care homes to offer respite break options for people living with dementia and carers. The argument that good, regular, affordable breaks can enable carers to care for their relative living with dementia in their own home for longer is one that the wider care system needs to recognise perhaps building on the recent policy commitment to investing some limited funding in respite services in England (Department of Health & Social Care, 2021).

Limitations and strengths of this study

Findings in this paper are limited in that they do not include the views of people living with dementia and draw on those of carers and other stakeholders only. This is because, in the sample we recruited, carers undertook the planning and

booking of the respite place. Sample size meant that analysis by ethnicity was not practical. A key strength of our study is the indication that Andersen's model in social care may be adaptable and useful to understand how the path from needing a service to using it may not be linear, and to identify factors that need to be addressed to make the option less onerous. The views of both carers and stakeholders make this a rich holistic perspective on the subject. Moreover, carers included those who had, had not, and were awaiting a period of respite, thereby providing multiple perspectives on contemporary processes of planning and booking a respite break. Future research should include observational studies that offer insights into how people prepare for, react to and are supported in a respite stay. Our study indicates the need to enquire about socio-economic circumstances and how these impact on planning and usage, as well as market shaping.

Conclusion

Planning, other than in crisis, and ease of booking the service were crucial elements for carers when seeking RR as well as addressing the complexities of payment arrangements. Respite should be considered during professional consultations and care planning with carers and people living with dementia, especially for those who lack contact with carers in similar positions and cannot draw on others' experiences. Planning can be discussed before and when a need is identified, and including it in conversations surrounding routine assessments and care planning opens up the way for discussions about using respite and other sources of support.

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No potential conflict of interest was reported by the authors.

Description of authors' roles

K.Samsi was the principal investigator of the study, designed the study, supervised data collection, assisted with analysis and wrote the paper. K.Orellana was a co-investigator, undertook recruitment, data collection, contributed towards thematic discussion and assisted with writing the paper. L.Cole was a co-investigator, undertook recruitment, data collection, contributed towards thematic discussion and assisted with writing the paper. J.Manthorpe was a co-investigator and the senior member of the team, who provided supervisory input and assisted with writing the paper.

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