



Understanding Break Needs, Break Experiences and Break Outcomes over the Care-giving Career: A Narrative Approach

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Chapter four: understanding break needs, break experiences, and break outcomes over the caregiving career: A narrative approach

Abstract

UK social care policy recognises the importance of short breaks for sustaining caregiving relationships, however, there is limited understanding of how unpaid carers' break needs evolve in response to the degenerative course of dementia and how these are supported. Using narrative analysis, the stories of 13 spousal carers for people living with dementia were used to construct an experiential description of the caregiving career, in which spousal carers evolving break needs, experience of accessing breaks and desired break outcomes were explored. The caregiving career was marked by the continual adaptation and acceptance of acute and gradual changes to the caregiving relationship which influenced breaks needs. Irrespective of when in the caregiving career, the process of deciding upon a meaningful break was relational and emotive, emphasising the relevance of relational support to aid transitions to breaks of mutual value. With the deepening cognitive impairment of the person living with dementia, spousal carers encountered difficulties in achieving breaks due to relational and service factors. The conceptualisation of caregiving as a series of shifting configurations underlines the necessity for ongoing and skilful practitioner engagement to help unpaid carers consider *what matters* to them, and proactively respond to changes in *what matters*.

Key words: Break options, Carers, Dementia, Narrative approach, Respite, Social care practice

Teaser Text

Caring for a spouse or partner living with dementia can be challenging. Short breaks from caregiving routines and responsibilities can make a positive difference to unpaid carers' health and well-being and increase satisfaction with the caregiving role. There is little research exploring unpaid carers' changing needs for breaks and how these are supported. Based on the stories of 13 spousal carers,

we explored how spousal carers experienced breaks as their partners' dementia progressed. Breaks were important to sustain or strengthen caregiving relationships, however, as the needs of the person living with dementia grew more complex, the process of finding a meaningful break took time and involved compromise. Our findings highlight the importance of knowledgeable practitioners who can skilfully support unpaid carers to reflect on and define *what matters* to them; this can help promote unpaid carers self-awareness to make effective choice of break(s). Reflecting the diversity of preferences and interests of spousal carers and their partner with dementia, having choice of flexible breaks options, including the option to experience breaks *together*, were important to deliver meaningful outcomes. As break needs change, relational support to enable transitions to different types of breaks was important to ease associated anxieties.

Introduction

Dementia is a progressive irreversible disease. Globally, dementia is one of the leading causes of disability and care dependency (World Health Organisation [WHO], 2021). Ageing remains the biggest risk factor for developing dementia. Population ageing, characterised by the rising proportion of people aged 65 years and over (United Nations, 2020), is driving dementia prevalence, and by 2030 it is estimated that there will be 78 million people with dementia worldwide (WHO, 2021). The challenges posed by dementia to care systems are complex and underscored by a global cost estimated at 1.3 trillion US dollars (Pickett and Brayne, 2019). Over half of this cost is attributed to the care provided by unpaid carers i.e., family, friends, or neighbours (WHO, 2021) (hereinafter referred to as carers).

Notwithstanding the positive aspects to caregiving, such as personal growth and accomplishment (Doris et al., 2018), dementia caregiving is associated with significant risk to carer health and well-being (Richardson et al., 2013). Caregiver burden refers to the subjective adverse effects on the carers' well-being when the perceived demands of caregiving exceed their available resources to manage these demands (Zarit et al., 1986). Caregiver burden is associated with depression (Epstein-Lubow et al., 2008) and poor health (Cheng, 2017), which can compromise the

quality of the caregiving relationship (Isik et al., 2019) and lead to premature admission to a care home for persons with dementia (Etters et al., 2008).

Through providing opportunities for carers to look after their own well-being, short breaks can help reduce caregiver burden and strengthen caregiving relationships (Tretteteig et al., 2017a; Vandepitte et al., 2016). A short break is any form of service or assistance which enables the carer(s) to have sufficient and regular periods away from their caring routines or responsibilities. The purpose is to support the caring relationship and promote the health and well-being of the carer, the supported person, and other family members affected by the caring situation (Shared Care Scotland, 2017).

Break length, break location, break activity, and break provider can vary. UK social care legislation (e.g., Care Act (England) 2014; Social Services and Well-being (Wales) Act 2014), emphasises care and support should help people achieve the outcomes that matter to them in their life, therefore, there is an inherent element of personalisation in the provision of breaks to support meaningful outcomes (i.e., a meaningful short break). Miller and Barrie (2016) identified meaningful break outcomes as improved satisfaction and choices in caregiving, a strengthened caregiving relationship, and the ability for carers to have *a life of their own*.

Despite carers frequently expressed need for breaks (Carers UK, 2021), the utilisation of break services remains low, and satisfaction with break experiences and the outcomes realised are poor (Neville et al., 2015; O'Shea et al., 2017). This disparity highlights fundamental knowledge gaps in understanding carers' needs for breaks and how they are supported to achieve meaningful outcomes (Seddon and Prendergast, 2019).

The degenerative course of dementia continually alters and reconfigures the nature of care-related responsibilities. Compared to carers for adults with other conditions, carers for persons with dementia provide more years of caregiving at home and care-related responsibilities generally increase in scope and intensity with disease progression (Alzheimer's Association, 2019). Seminal research by Pearlin and Aneshensel (e.g., Pearlin, 1992; Pearlin and Aneshensel, 1994) on the

longitudinal experiences of spousal carers for persons with dementia offers a description of caregiving as a '*continually shifting terrain*' (Aneshensel et al., 1995, p.70), denoted by changing circumstances that gives rise to unpredictable adaptational challenges. Aneshensel et al., (1995) conceptualise the evolving character of caregiving and role-related responsibilities as the *caregiving career*. This career trajectory is not determined by personal ambition but by the pathogenesis of the dementia and the resultant dependences it creates; the career, therefore, is an unexpected one.

Understanding the changing nature of carers' break needs over the *caregiving career* is essential if we are to effectively guide the work of practitioners engaged in assessment and support planning and the work of commissioners in utilising available resources to realise the preventative role of breaks. This line of enquiry is pertinent to the implementation of UK social care policy and that of other high-income countries, including Australia (e.g., the Integrated Carer Support Service), the USA (e.g., the Lifespan Respite Care Reauthorisation Act of 2019), and Sweden (e.g., The Social Services Act, 2011: 328) which advocate for the provision of breaks as a preventative measure throughout the *caregiving career* underpinned by principles of personalisation and choice.

This study adopts the career perspective of caregiving to orient attention to the temporal sequence of events. We use the construct of the *caregiving career* to explore the evolution of carers' break needs allied to the progression of dementia. We explore carers' experience of accessing breaks, including the provision of information, advice and support, and the availability and choice of break options. We consider desired break outcomes within the context of dementia spousal relationships.

Method

Narrative inquiry is a way of understanding experience (Polkinghorne, 1988). Harnessing the natural propensity for humans to compose and make sense of their reality through storytelling, narrative allows for an emic perspective of individual or collective lived experience across time within a particular social milieu (Connelly and Clandinin, 1990). Narrative inquiry has been used to understand the experience of carers for people with dementia, how carers articulate their support

needs, negotiate identities, and endow their caring role with meaning (Tretteteig et al., 2017b; Varik et al., 2020; Witham et al., 2018). The biographic narrative interpretive method (BNIM) (Wengraf and Chamberlayne, 2006) adopted in this study supported a holistic psychosocial inquiry of lived experience.

Ethics

Ethical approval was granted by the School of Medical and Health Sciences Academic Ethics Committee (2019-16563), Bangor University. Potential benefits for carers of sharing their story were the cathartic effect, and the opportunity to voice their reality and have it heard. However, there was a risk that the revisiting of stressful events, or worry for the future, could cause emotional distress. To minimise the potential distress, carers were reminded that they could stop or pause the conversation at any time and a list of organisations offering professional support was available.

Data collection

The study was conducted in a region in Wales, United Kingdom (UK). Purposive sampling was used to identify spousal carers willing to articulate their break experience(s). Recruitment was supported through members of the study's Project Engagement Group and local third sector carer organisations. Participants (n=13) received a bilingual project information sheet and formal consent was gained. Interviews were conducted between March and September 2021. They were conducted remotely, in line with COVID 19 regulations, either by telephone (n=9) or using the online platforms Zoom or Microsoft Teams (n= 4). Interviews were recorded and data securely stored in compliance with General Data Protection Regulations.

Personal narratives were elicited via the BNIM (Wengraf and Chamberlayne, 2006). Compared to semi-structured interview format, this method permits participants the psychological space for reflection and devoting time to what *they* deem meaningful to their story. A generative question, inviting participants to tell their story, was asked:

“Please tell me about your story of caregiving, taking me through the support you have received that has helped you in your caregiving role, and the ways you have been able to experience

breaks from your caring responsibilities and routines. You may start at any point in time that feels right for you.”

Once participants reached a natural conclusion to their story, specific questions, based on individual narratives, were asked to gain greater insight or for clarification. Further questions were then posed about how meaningful breaks were supported. The duration of interviews ranged from 60 to 90 minutes.

Participant characteristics

Eleven narratives were from spousal carers whose relationship with their partner predated the onset of dementia and continued to evolve as the dementia progressed; the longest marriage was 67 years. Two narratives were provided on behalf of spousal carers by their adult daughters who were involved in supporting their parents and shared their parents’ story. Spousal carers’ age ranged from 69 years to 87 years; the mean age was 76 years. People living with dementia ranged from 66 years to 94 years of age; the mean age was 80 years. Three people living with dementia were diagnosed with an additional neurological disease, and one had long-term physical disabilities. Three were bed ridden and being cared for at home. Within the last two years, three had moved into nursing or residential care and one person with dementia had died.

Data analysis

The interpretative and analytical process reflected a holistic-content approach as described by Lieblich et al., (1998). This approach preserves and embraces the narrative as whole, allowing for the sequencing and progression of events distinctive to the *caregiving career* (Andrews et al., 2013). As such, this approach is well suited to Wengraf and Chamberlayne’s (2006) recommendation for interpreting data elicited via the BNIM, in which the lived experiences of participants are chronologically structured, and the dynamics of ‘whole cases’ can be compared and used to lay the basis for theorisation.

Transforming interviews into a storied description started with the transcription of interviews. Immersion and familiarisation with the content was supported through several readings.

Next, the storyline was crafted by attending to two flows of decision-making (Wengraf and Chamberlayne, 2006). Firstly, the flow of decisions about carer's lived experience (i.e., objective life events revealed through their narrative), and secondly, the flow of decisions in the *telling* of how breaks were experienced, and the meaning and emotional responses ascribed to those experiences. Forming a coherent textual narrative involved an element of narrative smoothing (Kim, 2016) and the judicious selection of aspects of multiple individual stories that best illustrated shared experience. The software package Atlas.ti 8.2.34. (Friese, 2013) helped organise the data and facilitate data searching. Carers were assigned a pseudonym to protect their anonymity.

Findings

The caregiving career

In this study, the *caregiving career* is based on the stories of 13 carers and begins from formal diagnosis. While there were periods of stability, the degenerative course of dementia meant that over time the intensity and range of caregiving responsibilities for all carers gradually increased. For some people with dementia, the presence of comorbidities exacerbated the progression of dementia and increased the complexity of their care and support needs. Acute functional decline of the person with dementia was often the result of a fall or infection that required hospitalisation. The changing nature of the relationship influenced carer's sense of identity and couple hood. Over time, the range of activities that couples enjoyed together, such as walking, cultural activities, intellectual conversation, and travel, became less frequent and practically and emotionally more tiresome to arrange. Caregiving in older age (65 years +) exacerbated emotional vulnerabilities, such as lack of self-confidence and assertiveness, which made navigating health and social care systems difficult without guidance from practitioners. With career progression, a multitude of interrelated factors, such as escalation in caregiving and household responsibilities, increasing care dependency and distress shown by the person with dementia, and monotony of caregiving routines, left carers feeling overwhelmed and exhausted by their caregiving role. Sleep disturbances affected the quality of life for the couple and the distress shown by the person with dementia posed new challenges for carers

who had to adapt home environments and daily routines and learn new ways to communicate and comfort their partner during periods of confusion or distress. For those people with dementia who did transition to a care home, the balance of carers' responsibilities shifted from physical care tasks towards providing emotional reassurance, so their partner felt comfortable in their new home and retained a sense of purpose and agency.

Break needs

Following the formal diagnosis of dementia there was a period, varying from a few months to several years depending on how advanced the dementia was at the time of diagnosis, where couples' need for breaks reflected their pre-existing routines. For Mark and his wife, they continued to take breaks away together through their local tour company. During these breaks, Mark had minimal responsibility and could relax in the company of his wife;

"We have been all over the country with {tour company} ... going on these tours, everything's laid out. You get different attractions...'Cause it's a lot of stress, if we went somewhere on our own you've got to find something to do. You get a full cooked breakfast in the morning, and you get a three-course meal at night...I don't have to drive."

Over time, the cognitive and physical functioning of the person with dementia deteriorated. Catherine acknowledged due to her partner's deterioration the time for going abroad on holiday had passed;

"[Husband] has been dying to go on holiday, we always to go [country], but to entertain that with him how he is, if he gets any worse, that would be difficult".

The declining self-care capabilities of the person with dementia meant that the caring role intensified, and carers recalled feeling more consumed by responsibilities with less time for themselves;

"I see from everything from his clothes to his tablets and making sure he has a shower. My time has virtually disappeared...I am just tired all the time." (Catherine)

Carers reflected on the former aspects of their relationship that they missed. Louise remarked on her mother's sadness at the fading of activities that her parents previously enjoyed together and that offered her mum a break;

"Breaks were going to pubs for lunches and going for nice walks...But he, as time went on, just got less confident about walking very far...he would rather just sit in his comfortable chair where he felt safe and secure. And that was really frustrating for Mum."

Reflecting these transitions in the relationship, carers' needs for breaks were so they could continue to nurture their well-being through activities, friendship, and reciprocal support. They relied more on their community, friends, and family, to achieve this;

"Conversation is limited...I think twice before I say anything, which doesn't make for spontaneous conversation...I go on a Monday morning to the leisure centre, I really enjoy it and it's so nice to see different people." (Molly)

Community groups or clubs, designed for carers and/or people with dementia, were identified by five carers as providing a break from their caring responsibilities, and as a source of reciprocal support and learning;

"The most important thing in my month was the day at [carers charity's club], because you got to share your problems and find out information and know you are not alone....Just having a day with other people in a similar situation that was the best part." (Bianca)

Carers reflected on their own health concerns which made caregiving harder. Coupled with the increasing dependency of their partner and intensity of care responsibilities, break needs were for sufficient time to disengage from their caregiving role, psychologically and physically. Carers spoke of needing longer and more consistent breaks that helped them relax and revive their energy levels. In-home break provision, where replacement care was provided by a paid care/support worker, commonly once or twice a week, for two hours, was deemed insufficient to meet carers' break needs as their career progressed;

"It did help but I still needed a lot more than that...It was only two hours once a week, that is not a lot out of 24 hours, when you have the other 22 to do." (Caroline)

For five carers, after many years of caregiving at home, they acknowledged the physical care or behavioural support needs of their partner were beyond what they could confidently and sustainably meet. On balance, it was in both of their interests for the person with dementia to permanently move to a nursing or residential home. However, the caring role continued, and carers needs for breaks remained high. Geraldine described how she relaxed and restored her energy so she could continue to support her partner in his new home;

"Even though he's in care, I'll never stop caring. I find it difficult because I worry about him emotionally...He's got a phone, he phones me a thousand times a day...and I just say the same, "Yes, it's fine"...in the night my head nearly splits...Since he's been in care, I go every three weeks to have a facial, body massage, pedicure, manicure, and I do feel an immense physical relief from that."

The experience of accessing breaks

In the beginning of the *caregiving career*, community activities, that were either dementia specific or inclusive groups that welcomed people irrelevant of diagnosis, were perceived by many carers as an accessible, inexpensive, and consistent way of supporting regular breaks, with the added value of peer support. Jane explained how these groups supported her parents to preserve their sense of couple hood and social connections and brought structure to their week;

"They were attending local community groups, boules and art and walking with friends, and with these regular activities, my dad was getting enough respite...they were doing activities with an older age group, citizens who were a bit more worldly-wise...they knew that my mum was showing some of these behaviours, but they just accepted it, and patiently answered the same question every few minutes."

The availability of inclusive or dementia friendly activities were dependent on where the couple lived. Following the diagnosis of her husband, Francesca proactively decided to move to a

town with a better variety of activities for people with dementia which would also enable her to have regular breaks;

“I decided, because we were rural, nothing going on, nothing to do...so I said, ‘shall we move to [town], we have friends up there... I looked into the kind of dementia activities, and there were loads, places I could take him and leave him for a morning which would help me.”

As time went by and carers grew uncomfortable leaving their partner by themselves at home, arranging a break required greater assistance. If the couple had children, they enabled their parent to have a weekend break. In some instances, adult children worked abroad, or due to their own family and work commitments, the support they could provide was temporary, and not a regular option. The prevailing perception around accessing timely support from Local Authorities to support breaks was one of challenges;

“The local authority will say, ‘we have this service and this service’ but, when you dig into it, they aren’t available either through lack of staff, lack of money or the ridiculous high criteria...There was volunteer buddy system that [Husband] was on the waiting list for over a year for, when I chased that up, they said ‘the waiting list is so long, realistically, you aren’t going to have anybody’.”
(Caroline).

Catherine recalled that despite being given information about break options, the lack of guidance to help her make sense of the information and talk through options meant she struggled to think about how her break needs could be met:

“I feel sometimes I get bogged down with it all, all this information and trying to take it all in... the things that they are telling us to take part in don’t really suit our needs. I do feel overwhelmed with everything that has been pushed in front of me.”

Bianca expressed her uncertainty in knowing where to look and who to ask for support in accessing a break and understanding her break options as circumstances changed;

“Some people, including myself, need a helping hand through these things, rather than being left to do it by yourself...clarity, on “this is the person you ring if you want respite care” ...and to give a roadmap of where you are on it and when you get to this point, we can do this, that and the other”.

The value of a practitioner who offered supported choice was relayed by Geraldine who spoke of the succour received from her local Carers Champion who listened and discussed with her the ways she could experience a break that would balance her and her partner’s needs. Day care was chosen as it was a steppingstone to eventual residential care;

“It was not leaflets I needed...I needed a person one-to-one, and the Carers Champion was on hand for me all the time...Without her I wouldn't have been able to help [husband]...she advised me, listened to me, helped me, she told me about day-care...If he hadn't gone to day care, he would never have settled in a care home”.

Communicative tensions were present between couples which made some carers feel guilty about articulating their break needs and taking a break. With the increase in caregiving responsibilities, Catherine described the sensitivities of explaining to her husband that she needed a break and time for herself;

“We were discussing whether it would be a good idea for me to get away for a while and his answer was ‘why would you want to do that’, and I said ‘to recharge my batteries because am I so tired’, and his response was ‘why are you so tired, I know you do a lot and you look after me, but you won’t let me do things and you won’t let me drive’ and then it goes on or we end up in an argument.”

Carers reflected on the limited choice and availability of break options for them to experience a full day for themselves, with day care or residential care being the two options referenced. Both options were caveated by contingencies and reservations pertaining to service factors (e.g., long waiting lists, care quality) and personal factors (e.g., reluctance of the person with dementia to attend, carer guilt). Felicity described her husband’s preference to stay at home, which meant that day and residential care were not deemed appropriate break options;

“We tried to get him to go to this day centre...a couple of times when [husband] was more in the mood of getting in the wheelchair and a car, we almost got him to go, and then he'd back off at the last minute and he wouldn't go.”

Edward described his experience of using Direct Payments to employ a team of carers to help him care for his wife and allow him to take a break for a couple of hours each week to go for a walk. Although the Direct Payments did offer control and flexibility over who he employed, the support provided by the Local Authority to help manage the Direct Payments was unreliable. Edward further described the pressures he faced in finding highly skilled and dedicated care staff to become part of his caring team;

“If I didn't have the ability to be as proactive as I have been and find things out for myself, then it wouldn't have been easy...they haven't got one person who the Social Workers can contact or anyone can contact who knows what happening with Direct Payments...we have been struggling to get the amount of care that [wife] should be having, it's so difficult to get a good carer...that is one of the main difficulties, finding suitable carers who you know and trust.”

Break outcomes

Regardless of when in the *caregiving career*, a break supported meaningful outcomes for carers when it enabled them to nurture the aspects of their well-being that mattered most, whether this be solitude or time with their partner but in a new environment that offered a pleasant change from caregiving routines.

Following a break, carers commented on their increased compassion within the caregiving relationship, energy to be in the present moment with their partner, and patience to communicate with empathy;

“Because you've had a break, you've got more patience”. (Rebecca)

Feeling rested and relaxed was an important outcome for Francesca and helped sustain her caring role;

“We stayed at this beautiful hotel, we went to dinner together, we sat on the balcony, and it was lovely and sunny...I felt the benefit of it, not having to cook and not having to drive”.

Felicity shared how the affection and support that was once mutual in their relationship had gradually become unilateral, and this relational shift influenced her desired break outcomes;

“The thing that's difficult to acknowledge is that I've become very unrelated to him...the more I've become a carer, the less I'm a partner, so the less I'm relating as somebody whose company I enjoy...there are times when I've been really upset about something, and he will momentarily be able to be there for me, but it will be gone the next time we have a conversation ...the thing that I want more of is solitude.

For breaks taken apart, it was important that carers perceived the experience as being of mutual value for their partner and supported their well-being outcomes. Caroline wished her husband had access to activities that utilised his skills and capacities, instilled a sense of worth and bestowed a sense of achievement;

“[Husband] was an active man who did a lot of sports, windsurfing, skiing, cycling. Sitting around in a group doing chair aerobics, was not good...somebody like him needs that one-to-one or a group of similar people who would take him out and do activities but could manage his toileting and food to enable him to enjoy life.”

Edward's desired break outcome was simply having time to do as he pleased without expectation or pressure. He illustrated the impact of having a full day break;

“I can go for a walk now without having to look at my watch during the respite week...It just gives me the chance to breathe and switch off a little bit, it takes three days at least for me to acknowledge that she isn't in the house, and I don't have to check on her.”

Where replacement care was needed to facilitate a break, person-centred care was central to delivering meaningful break outcomes for the people with dementia and for carers. Edward described the reassurance he gained from knowing that the staff caring for his wife were

compassionate and highly trained to meet her complex needs. This assuaged any worries and guilt about experiencing a break;

“[Wife] went for a week there, and because of staffing they have got there, they have obviously got doctors, they have qualified nurses, they have got support workers, and physios they could look after [wife] needs because of the nature of their work. I wouldn’t let her go anywhere else...it’s the only place I feel happy letting her stay.”

Discussion

This study offers an interpretative description of the *caregiving career* in which carers’ break needs, experience of accessing breaks, and breaks outcomes were explored. A range of breaks of varying lengths and activities were sought throughout the *caregiving career* to promote well-being and sustain the caregiving relationship. The need for breaks continued after the person with dementia moved to a care home. The career trajectory was marked by the gradual transition from informal community activities that offered a break, to formal services with increasing support from health and social care professionals. It was in these transitions where delay and lack of choice of break options caused difficulty for carers to access timely breaks and achieve meaningful outcomes. Our discussion henceforth focuses on how breaks can be maintained throughout the *caregiving career*.

The process of deciding upon a break was typified by many deliberations and the balancing of priorities, needs, preferences, and opportunities, including the opportunity to take a break together. This elevates the importance of exploring and understanding *what matters* to carers during assessment and support planning. Practitioners who undertake Carer’s Assessments (CA) or lead ‘What Matters’ Conversations (in Wales) have a vantage, yet complex task, to creatively guide conversations with carers to encourage them to identify the outcomes that matter to them, and to use that understanding to personalise break options which might support their achievement. Supported choice and personalisation of break options can be fostered through the relationships and communication with practitioners, specifically through engaging with the nuances of the

caregiving situation and relationship, where individual and relational strengths and capabilities, as well as vulnerabilities, resources, and support networks, are discussed to inform short break priorities and short break outcomes. The importance of the carer-practitioner relationship is shown by MacBride et al., (2020), who found interactions with skilled practitioners helped carers to feel valued, heard, and to articulate their priorities to support their well-being and their caregiving role. Our findings lend support to research that advocates a conversational and relational approach to developing personalised support plans founded on the exchange of views and expertise to enhance carers' self-awareness to make effective choices (MacBride et al., 2020; Miller and Barrie, 2016). Figure 1 illustrates the principles identified as central to the assessment and support planning and the commissioning process to deliver meaningful short break outcomes.

The review of caregiving circumstances should be an ongoing process throughout the *caregiving career*, to identify where changing circumstances might pre-empt fluctuations in break needs and desired break outcomes. O'Shea et al., (2017) alluded to the importance of supporting the transition to the use of break services. We augment this practice recommendation by adding that supporting transitions to different break lengths, break activities, and break providers, are necessary. Impartial relational support by practitioners is needed to legitimise carers' need for and right to breaks, and ease associated anxieties, particularly in the context of breaks taken apart where carers can experience guilt or the person with dementia expresses hesitancy to enter unfamiliar environments and may benefit from a phased introduction to breaks. If the person with dementia should move to a care home, carers' continuing break needs should be recognised by the professionals supporting this transition.

While traditional service models, such as day care and residential care remain important options of choice, improving access to a wider range of flexible and personalised break options is a priority for the Welsh Government Strategy for Unpaid Carers (Welsh Government 2021a). Reflecting the preferences of some couples in this narrative to take a break together, inspiration can be drawn

from the Scottish model of respite which collaborates with the tourism, hospitality, and leisure sectors to offer breaks that cater for individuals, couples, and families.

Substantiated in this narrative is the complexity of caring for someone living with dementia. Carers' multi-layered support needs necessitate involvement and input from a multi-disciplinary team of health and social care professionals. To maximise the break experience and outcomes, break options should form part of an integrated offer of support, which may involve a combination of peer support, therapy or counselling, psychoeducation, or skill-based training to promote learning about dementia, teach coping and self-care techniques, advise on ways to effectively respond when the person with dementia is distressed, and prepare for transitions in the caring role.

Our findings emphasise the need for a single professional contact, introduced to carers from the point of diagnosis, with responsibility for coordinating carers' support needs, including breaks, throughout their *caregiving career*. Reflecting the considerable diversity in commissioning and delivery arrangements for breaks (Caulfield et al., 2021), there needs to be local, and where feasible regional agreement on the professional(s) responsible, and how they form part of an integrated post-diagnostic support team for carers and people with dementia; this is key to simplifying the pathway to timely breaks as part of a holistic approach to supporting carers' well-being. This perspective closely aligns with findings from the European Actifcare study (Access to timely formal care) (Kerpershoek et al., 2019). A key recommendation was that people have a named contact person who continuously maintains contact, cooperates closely with primary care services, offers individualised information, advice, and support, and regularly assesses the needs of the person with dementia and their carer/family.

With the decline in the health of the person with dementia, the availability and quality of replacement and/or personal care were central to realising meaningful outcomes. Across the UK, the long-term failure to invest in the social care sector has given rise to considerable challenge in the recruitment and retention of the adult social care workforce. This increases the difficulty of commissioning because the market and availability of breaks is inextricably affected by the broader

state of health and social care. The Rebalancing Care and Support report (Welsh Government, 2021b) acknowledges high staff turnover, costly recruitment and training of new staff, and increased use of agency staff as systemic barriers to workforce sustainability. It is imperative that the UK devolved governments follow through on commitments to improve pay and employment conditions in the social care sector to deter the 'casualisation' of caring and raise the status of social care as a profession.

Study limitations

The 'trustworthiness' of narrative studies is an important methodological consideration (Lincoln and Guba, 1985). In narrative epistemology, knowledge and experience of the world is malleable and propels an ever developing and evolving narrative. Carers' perspective on past experiences were told from the vantage of a particular moment in the present, subject to conscious and unconscious selectivity (Spector-Mersel, 2010). Future research could adopt a longitudinal approach and capture insights in real time. While it was not the focus of this study to verify the accuracy of carers' stories, their verisimilitude was supported through questions that qualified and clarified events, as to learn of their transformation and resolution over time, and the meaning ascribed to them.

Multiple stories were compared to look for commonalities in lived experience and the meaning accrued to those experiences. The narrative presented is not an exclusive nor 'perfect' creation that can claim to fully capture and reveal the complexities and nuanced experiences of its multiple authors, rather it is a partial interpretation of realities experienced and retold through the subjective and perspectival lens of the researcher.

The concept of a *caregiving career* can be criticised for misrepresenting caregiving as a formal 'occupation', overlooking the reciprocity of many interdependent caregiving relationships. Indeed, for many spousal carers, caregiving is a natural extension of their marital role and they do not identify with the term 'carer' (Larkin et al., 2020). It should be stated that the *caregiving career* can start years before the formal diagnosis and therefore this study does not reflect this important often

invisible phase of caregiving. However, for the purpose of this study we focused on provision of breaks after diagnosis to avoid issues around eligibility for services.

The samples lack of ethnic diversity limits the transferability of findings, as different ethnic cultures have shown to influence ways of coping and engagement with formal support services (Johl et al., 2016).

Conclusion

The construct of a career trajectory was helpful to appreciate the commonalities in experience of realising breaks by carers embarking down a dementia caregiving path. Drawing on other temporal models of care (e.g., Cavaye, 2008; Wuest et al., 1994), future research could use clear descriptors of the stages of dementia caregiving to illustrate the break models and options that carers are likely to need and accept at specific stages in their career. The evolving break needs identified in this study could contribute to this work.

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