# Continuous Change as a Disruptive Force: Exploring Homecare Transitions for Carers of People Living with Dementia in Scotland

RESEARCH

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## ABSTRACT

Due to an ageing population and strategic moves away from institutional care, the number of informal carers supporting a person living with dementia in Scotland is set to rise. The shift toward community-based care means that informal carers are often in contact with homecare workers during a transitional period between being the primary carer and sharing care with homecare workers. As part of the findings from a larger study that focused on the experiences of co-habiting carers of a person living with dementia when homecare began, this article presents 'continuous change as a disruptive force' as a key concept of carers' experiences of transition. Recognition of continuous change for carers can inform our understanding of transitional processes and ways in which homecare providers' response to change has considerable impact on carers' transitional experiences. Interview data were generated remotely with five participants in Scotland. Two participants completed eight interviews over a period of six months. All data was collected between June 2021 and December 2021. Data were collected by telephone, online video meeting (Teams), and in one instance by email and analysed using reflexive thematic analysis. This article focuses on disruption through change caused by dementia – including unpredictability and impermanence, and homecare providers' lack of responsiveness the closer to crisis participants became. In conclusion, the experiences of transitions to homecare for those caring for a person living with dementia are multiple, complex, and perpetual. I recommend subsequent research into reducing liminal periods for people encountering non-normative transitions and suggest that homecare providers focus resources on providing consistent and reliable services and on training staff specifically in carer support.

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## BACKGROUND

Due to a rapidly ageing population and strategic moves away from institutional care, the number of informal carers supporting a person living with dementia in the community is set to rise. This article will contribute to the body of literature that will later inform policy and practice in homecare service provision through accessing and analysing the stories of informal carers who were experiencing a transitional period between being the primary carer and receiving paid homecare services in their home.

According to the WHO's global status report on the public health response to dementia (WHO, 2021), an estimated 55 million people currently live with dementia globally, and this is expected to rise to approximately 139 million by 2050. In Scotland, the number of people living with dementia is estimated at 90,000 (Scottish Government, 2017a) although because these figures rely on reported diagnostic rates rather than reflecting the number of people living with symptoms of dementia, it is likely that these are underestimations of the true figure.

As the numbers of people living with dementia increases, there is a proportional rise in people taking on informal carer roles. Informal care accounts for almost 50% of the global cost of dementia care, accounting for approximately 89 billion hours in 2019 (WHO, 2021). Although no figures are available of the number of people caring for someone living with dementia specifically, the WHO (2021) estimates the number of work hours given to informal care globally is equal to about 45 million full-time workers. Of these figures, approximately 700–800,000 people in Scotland were providing informal care in 2019, rising to an estimated 839,000 in 2020 (Scottish Government, 2022).

Given the estimated increases in the age of the global population and the prevalence of dementia, it has become crucial that legislative, and strategic support for informal carers has increased over the past ten years. In Scotland the most prominent legislative support was the publication of the Carers' (Scotland) Act 2016, which came into force in April 2018, and the accompanying Carers' Charter (2018). The purpose of the Carer's (Scotland) Act (2016) is to promote carers' physical and emotional wellbeing through individual assessment and (if eligible) access to support such as short stay respite provided by local authorities. As a companion to the Act, the Carers' Charter (2018) was designed to help people to identify themselves as carers, to understand their rights and to understand how to access those rights.

In addition, Scotland's National Dementia Strategy (Scottish Government, 2017a), the Age, Home and Community strategy for housing Scotland's older people (2011) and the Health and Social Care Standards (Scottish Government, 2017b) present informal carers as a crucial part of Scotland's care infrastructure and seek to put their needs at the forefront of care provision. Whilst independently these strategies promote carer wellbeing, there is not yet sufficient understanding of how informal carers (in particular, people living with dementia), and those who provide paid homecare services interact, or how this affects informal carer experiences.

More recently, the Covid-19 pandemic brought about the Scottish Government's publication of a dementia and Covid-19 action plan (Scottish Government, 2020). This detailed what was known about the impact of the pandemic at that point on people living with dementia, as well as those providing informal care and using care services. The action plan recognised the considerable pressure placed upon a growing number of informal carers of people living with dementia in Scotland at the time of the pandemic and put steps in place to alleviate pressure by increasing support.

In many high-income countries over the past twenty years, there has been a shift from a traditional trajectory that sees people with dementia moving from the community to residential care, to a model in which people with dementia are encouraged to stay at home for longer (Vanleerberghe et al., 2017) and for many this is their preferred choice (Lehnert et al., 2019). Supported by Alzheimer Scotland, the Scottish Government have encouraged people living with dementia to maintain their independence by remaining in their community for as long as possible (Scottish Government, 2011; Scottish Government, 2017a). Indicative of a broader global shift towards 'ageing-in-place' and living at home for longer, the repositioning of the place of care risks transferring the responsibility of care onto informal carers for longer periods of time (Milligan, 2015; Broese van Groenou & De Boer, 2016). Informal carers are more often expected to provide care until much closer to the person with dementia's death, than to consider instutionalisation as an earlier option. This shift means that a new dynamic is also created whereby informal carers and homecare workers become co-workers of a kind with one another, during which the boundaries of responsibility and role can sometimes become blurred (Singh et al., 2014).

### TRANSITIONS IN CARING FOR A PERSON WITH DEMENTIA

The literature on transitions for informal carers of a person living with dementia has primarily focused on the transition between home and an institutional context, and over the past fifteen years has seen a shift from primarily quantitative research to qualitative approaches.

The process of relinquishing the role of primary carer to an institution is often perceived as stressful and traumatic to many (Groenvynck et al., 2021; Lee et al., 2022; Lewis, 2014), and can be a transitional period that constitutes one, or multiple, losses (Cottrell et al., 2020).

The carer experience is widely reported as being complex and constituting multiple paradoxes, such as a sense of relief alongside guilt, or a need for respite but a desire to stay close (Crawford et al., 2015; Groenvynck et al., 2022; Høgsnes et al., 2014; Lee et al., 2022; McCormack et al., 2017; Cronfalk et al., 2017). Not all transitional experiences of informal carers of a person living with dementia are exclusively negative and often some positivity comes to light at the same time as acknowledging sadness (Johansson et al., 2014; Moon et al., 2017; Pritty et al., 2020; Rondon-Sulbaran et al., 2021).

Based on what is already known about carer experiences of transitions for the person with dementia, this study has been designed to be novel in three ways: Rather than using a pre-post-test experimental approach, or retrospective accounts, it uses a design that maintains contact with the carer during the early part of the transitional period. The carer nor the person living with dementia moves to another environment, which is likely to deeply influence the transitional experience. The use of Multiple and Multidimensional Transitions theory to guide analysis facilitates a view of transition that welcomes the complexity and paradox that previous literature has shown to be expected.

## CONCEPTUALISATIONS

### TRANSITIONS THEORY

During the carer journey there can be a great number of transitions, including for some the process of self-identification as a carer, changing relational identities, transitions in physical environments and emotional or psychological changes. For the carers in this study, the focus was on the transitional period of moving from being the primary co-habiting carer toward sharing the care role with homecare workers or relinquishing it all together. In this article, the conceptualisation of transition as multiple, dynamic, interconnected processes was guided by Multiple and Multidimensional Transitions (MMT) theory (Jindal-Snape, 2016). Taking a transitions approach to this research provided a lens through which experience was viewed as fluid and complex. The carers in this study were not simply exchanging one role or identity for another, or moving in a linear trajectory, but moving between many connected processes of their own transitions and those of others. MMT theory (Jindal-Snape, 2016) was central to my interpretation of the study findings, and the development of my discussion of liminality and transitional periods.

As discussed in Jindal-Snape et al. (2019), I considered the carers' transitional period to be *non-normative*. By this, I mean that although many of us expect to care for others in our family during our lifetimes, there is no external framework that tells us when, how, or for how long that might happen. The diagnosis of dementia, in particular, meant that even when a person realised they were becoming an informal carer, there were still many unpredictable variables such as the way in which the progression of dementia was not linear – improvements in independence were made and lost. There were long periods of little change and then a sudden influx of symptoms. And the overall trajectory of the disease did not have a timeframe or recognisable pattern.

This differs from educational research, for example, in which a *normative* transition might mean movement from one year group to another, more advanced year group, at (generally) the same age – this is an expected life event for most people who live in places where education is widely available. In this article I argue that transitions in caregiving, particularly for caregivers of people diagnosed with a degenerative condition, pose a different sort of experience, or rather, a different set of challenges, than those of a person who is experiencing a normative transition.

### THE CONCEPT OF LIMINALITY

Liminality is a concept that is central to the discussion section of this article. In its simplest form, liminality is the sense of being in-between, neither here-nor-there. Founded in social anthropological studies of ritual and social processes, liminality was theoretically conceptualised as being in the middle stage of a linear transition process. The first stage of transition was separation (from a social group for example), followed by liminality (being outside of a social structure) and then aggregation (re-entry to a social group) (Noble & Walker, 1997; Turner, 1967; van Gennep, 1960). Contemporary literature has built upon this foundation to include studies of identity and the self (Dean et al., 2020; Gordon et al., 2020; Nord, 2021). I understand liminality to be a social, psychological, emotional, or physical state, in which a person feels a lack or loss of belonging during a time of change. A detachment from a social group, for example, having lost one social status but not yet gained another, or in the context of this study, fulfilling multiple roles at one time without feeling fully integrated into any of them.

### Terminology and Language

For brevity, in this article I will be using the term 'carer' to refer to people who are not professionally employed to give care and support to a person living with dementia, often terms such as 'unpaid' or 'informal caregiver' are used for the same purpose. I recognise that many people prefer other terminology including specific names and familial terms, but for clarity in this article I have chosen the term most commonly used in Scottish literature. I will refer to those employed to provide homecare as 'homecare workers' and the organisations that they work for as 'homecare providers'. This includes any paid homecare services, whether provided by local authority, private businesses or third sector organisations.

### Study Aim

The aim of the larger study, from which this article originates, was deliberately broad: To explore and describe the experiences of co-habiting carers of people living with dementia during a transitional period in which caring tasks become shared with, or relinquished to, paid homecare services.

In this article I focus on one key concept from the findings of the study: 'Continuous change as a disruptive force'. I will discuss how recognition of continuous change for carers can inform our understanding of transitional processes and ways in which homecare providers' response to change has considerable impact on carers' transitional experiences.

## METHODS

### METHODOLOGY

The research presented in this article is drawn from a larger longitudinal qualitative study on the experiences of co-habiting carers of a person living with dementia when homecare began. There were two phases to the larger study. The first phase was a single interview with each participant who had not yet begun homecare or were receiving less than six hours of homecare per week. The second phase was longitudinal and consisted of six secondary interviews and one semi-structured interview over a period of six months. The purpose of completing multiple interviews was to explore the day-to-day experiences that made up the transitional period, as much of the previous literature focused on retrospective accounts.

The key concept of continuous change was generated during analysis of the data from the longitudinal phase, and this is the featured focus of this article.

## STUDY APPROACH

In order to develop a study that was focused on the lived experience of participants, I chose a hermeneutic phenomenological approach to the study design (van Manen, 2016, 2017). I then utilised reflexive thematic analysis (Braun & Clarke, 2021) because it aligns clearly with the principles of the qualitative paradigm, facilitated my meeting the study aim, and was best suited to make sense of the complexity of the data generated in interview.

## STUDY DESIGN

The study was a longitudinal qualitative design that took place over six months and consisted of online and telephone-based interviews with co-habiting carers of a person living with dementia in Scotland. Interview data were transcribed verbatim and analysed taking a reflexive thematic analysis approach (Braun & Clarke, 2021).

This study was impacted by the national Scottish lockdown imposed in response to the COVID-19 pandemic in March 2020, and subsequent restrictions that continued into 2021. Restrictions on travel outside of the home affected my decisions around completion of carer recruitment and approach to data collection. Although initially disappointed not to be able to meet participants face to face, I came to realise that recruiting and interviewing carers online meant that those who were digitally literate faced fewer logistical challenges, particularly in terms of time requirements, in order to participate. This meant that I was able to contact carers in a wider geographical area than first anticipated.

## RECRUITMENT

I produced an informative recruitment video that was published on YouTube and a study information sheet. A link to the video was distributed by email to all departments within local authorities in Scotland that had contact with carers and to third sector carer support organisations, alongside an explanatory email and contact information. Twitter was also used to circulate the YouTube video link. Twitter is an online social media platform that allows links to information and short pieces of text to be shared freely online. For this study I chose to utilise Twitter as it was an already-established mechanism of information sharing for the university, is free and had potentially national reach.

A study profile was approved for the Join Dementia Research register site. This site allows people living with dementia, people who care for someone who is living with dementia, and those who work in dementia care to register their interest in participating in research and for researchers to advertise their studies. I emailed every person who had registered as a carer of a person living with dementia in Scotland, which totals approximately 200 people.

Ultimately, all five participants were recruited through the Join Dementia Register. Three participants accepted an invitation to have an informal telephone conversation to learn more about the study prior to giving consent. Following initial contact, potential participants were emailed a participant information sheet and a link to a digital consent form hosted on Microsoft Forms. Once completed, I contacted participants to arrange our first interview.

## PARTICIPANTS

To capture this very specific transitional period in their lives, potential participants in the study were required to have been co-habiting with a person formally diagnosed with dementia, as their main caregiver, for a minimum period of six months before data collection began. I asked that nobody in the household was receiving more than six hours of homecare services per week at the beginning of the study but that they were expecting homecare services to begin or increase in the next few months.

Owing to the specificity of the recruitment criteria very few potential participants were able to enrol in the study. Within the qualitative paradigm this is not problematic and meant that a great deal of energy could be applied to the generation of data and analysis of transcripts.

In the larger study, a total of five participants were recruited. Four women and one man were included in the study, the age range of whom was 38 – 77 years. Participants had been caring for the person living with dementia for between approximately two and a half and six years. All participants were given pseudonyms based on their ages. There were two daughters looking after their mothers, one daughter looking after their father, one wife looking after her husband, and one husband looking after his wife.

This article focuses on the longitudinal phase of the study, which was completed by two of the participants. Barbara, aged 38, was the primary carer for her father, and Margaret, aged 75, was the primary carer for her husband (See Table 1).

Reasons for not continuing with the longitudinal phase of the study were: One person that a participant was caring for had a medication review that resulted in a reduction in symptoms, so they felt there was less need for additional support; one participant's email address was not accepting emails; and one participant was approved for self-directed funding, but the recruitment of staff took longer than the data collection period for the study.

| | BARBARA | MARGARET |
|---|---|---|
| **Age** | 38 | 75 |
| **Relationship between carer and PLWD** | Daughter and father | Wife and husband |
| **Time since dementia diagnosis at first interview** | Approximately 4 years | Approximately 3 years |
| **Type and duration of homecare services received at interview 1** | 2 hours per week private respite<br>4 hours per week local authority homecare support for personal care | 6 hours per week local authority homecare support for respite |
| **Reasons for considering or requesting increased occupational care** | • Concerns about maintaining personal hygiene of father<br>• Barbara's need for respite | • Increased immobility of husband creating physical strain and safety concerns<br>• Rapid progression of Margaret's husband's dementia symptoms |
| **Participation in the study beyond the first interview** | Barbara completed a total of 8 interviews over a 6-month period | Margaret completed a total of 8 interviews over a 6-month period |

**Table 1** Longitudinal Phase Participant characteristics.

## DATA GENERATION

All data were collected between June 2021 and December 2021. Data were collected by telephone, online video meeting (Teams), and in one instance by email. I completed one semi-structured interview lasting approximately one hour with each participant at the beginning of the study. Following this, two participants went on to complete the longitudinal phase of the study which consisted of a further six secondary interviews, and then one final semi-structured interview six months after the beginning of the study (See Table 2).

Because recruitment was proving to be challenging during the pandemic, and contact with others was limited, the schedule for interview one was piloted with a family friend who was experiencing a similar transition to the people I recruited for the study. The pilot interview served to ensure that the recording processes for interviews were correct, and as a result of the pilot interview I made minor changes to the schedule to improve the logical flow of the questions.

| | INITIAL SEMI-STRUCTURED INTERVIEW | SIX SECONDARY-INTERVIEWS OVER SIX MONTHS | FINAL SEMI-STRUCTURED INTERVIEW |
|---|---|---|---|
| Barbara | Completed | Completed | Completed |
| Margaret | Completed | Completed | Completed |
| Participant 3 | Completed | Unable to complete | Unable to complete |
| Participant 4 | Completed | Unable to complete | Unable to complete |
| Participant 5 | Completed | Unable to complete | Unable to complete |

**Table 2** Overview of Longitudinal Phase Completion.

The initial semi-structured interview schedule consisted of nine questions that were grouped into three topic areas: ‘Where are you now?’ (participant focused), ‘What is changing, and how?’ (service focused), and ‘Where are you going?’ (expectations focused), along with general prompts designed to encourage participants to go into more detail where appropriate.

The secondary interviews were designed as a means of revealing more of the day-to-day experiences of the carers as things changed, an aspect that was missing from previous literature. The secondary interview lasted between twenty and forty-five minutes and consisted of two prompts: ‘Can you tell me how your life at home is feeling at the moment’, and ‘Could you describe to me anything that has stood out to you in the past two weeks or so in terms of the service you have been receiving?’.

The final semi-structured interview schedule echoed the initial interview by again asking questions that were grouped into the same three themes. During this final interview both participants reflected on their carer journey, and we spoke about how much had happened in the previous six months.

Carers who enrolled in the study were offered the choice of undertaking interviews by telephone or by Microsoft Teams video call. Four of the five participating carers chose to be interviewed over the telephone, and one carer preferred to use Microsoft Teams video chat. I recorded all interviews using Microsoft Teams which produced an automatically generated transcript. I checked transcripts for accuracy, edited, and anonymised them and securely stored them within the Microsoft Office Suite.

## ETHICAL CONSIDERATIONS

Ethical approval was gained for this study from the School of Education and Social Work, University of Dundee Ethics Committee in December 2020 (Approval number E2020-22). Informed consent was gained from all participants using Microsoft Forms, and consent forms were stored within the Microsoft Suite hosted by the University of Dundee in accordance with the data management plan. Transcripts were auto-transcribed in Microsoft Teams, then manually edited for accuracy and for anonymity then stored within OneDrive. Once analysis was complete, interview recordings were permanently deleted.

All interview data were kept securely and were only accessible to the research team, and transcripts were anonymised with great care to protect privacy, confidentiality, and anonymity. All quotes reported within this article are verbatim and represent participants’ actual speech as much as possible. Whilst I have been careful to be inclusive in this article, I acknowledge that cultural differences may mean that the language I have used may convey meanings other than those intended, especially in emotive subjects such as caring and ageing: I welcome discourse on this subject.

The key ethical considerations during this study are the psychological and emotional wellbeing of the carers who took part, owing to the sensitive and personal nature of the subjects we discussed. I spoke with all participants at the start of interviews to remind them that they were not obligated to answer all questions and that we could stop at any time, I was conscious of checking that the carer was happy to proceed during interviews in which they appeared to be distressed. All participants were made aware before and after interviews that they could contact me after the interviews if they felt they needed to. A resource list was also compiled in advance should any of the participants have felt they needed additional support; however, this was not necessary during the study.

I acknowledge that digital-only recruitment contributes to the perpetuation of the digital divide, excluding those who do not have access to the knowledge, equipment, or services necessary to participate online. The decision to recruit in this manner was taken as a result of the Covid-19 pandemic restrictions. The larger study was fully revised during 2020 resulting in the development of a new study protocol and ethical approval application, with specific focus on using online recruitment and data generation methods. These reflected the restrictions on travel, meetings, and Covid-19 related isolation periods at that time in Scotland, all of which meant that digital recruitment was necessary for the study to be completed within the funded period.

## DATA ANALYSIS

I collated and analysed transcripts from the sixteen longitudinal interviews following the process of reflexive thematic analysis (Braun & Clarke, 2019, 2021). Whilst transcribing and listening to the recordings of interviews, I thoroughly familiarised myself with the data. Through iterative cycles of inductive coding and grouping of excerpts and refining of both codes and groups in NVIVO I generated first semantic (descriptive), then latent (conceptual) themes. Four themes were developed using the reflexive thematic analysis approach, and 'continuous change as a disruptive force' was selected as the key concept of this article.

# FINDINGS: CONTINUOUS CHANGE AS A DISRUPTIVE FORCE

> 'You think "OK! I've got a handle on this", and then the next thing happens'. (Barbara, discussing the constant need for adaptation as a carer)

The concept of continuous change is central to the transitional experiences in this study. It became clear to me whilst completing the interviews with Barbara and Margaret that there were two predominant sources of change, both of which presented their own challenges and disruptions: Dementia itself, bringing with it the complexities of impermanent and unpredictable behavioural changes, loss of physical and cognitive abilities and subsequent changes in relationship dynamics; and homecare services, with their own impermanence and unpredictability, changes in staff and service provision, and responsiveness to changes in support needs. In the following section, Barbara and Margaret's stories are explored as they navigate change during the first six months of receiving homecare.

## THE FLUIDITY OF DEMENTIA

As a degenerative condition, the trajectory of dementia is such that people living with the condition are expected to experience increased need for support and care in order to continue to live independent and healthy lives. Though Barbara and Margaret understood this, the suddenness and sadness of change at times came as a shock, and the sometimes-unrelenting processes of change and adaptation as part of living with dementia were deeply challenging. Barbara is describing here a new change in her father's behaviour, and how it feels to be constantly adapting:

> '…it shocks me. It makes me feel really emotional because (you) just get used to something, you think OK I've got a handle on this, and then the next thing happens and you think "Oh, something's changed again"'. (Barbara)

When asked to describe something that felt significant in her life, Barbara continues by describing some of the changes that she recently experienced with her father and how that felt for her:

> 'The significant thing would be [pause] the realisation that his brain is dying. In that, I mean you, you know, you know that, or you know that that's what the condition does it, the brain deteriorates, brain function deteriorates but, it's like watching him slowly dying in front of my eyes'. (Barbara)

In a later interview, Barbara is realising that some changes in behaviour are permanent and signify something more about how quickly the disease is changing their lives. She talks here about her experiences of change in her father and how difficult it can be to keep adapting:

> 'You prepare yourself kind of mentally going into it, but then things that come up that you just, well, I guess the main thing would be the speed at which it's kinda [pause] how his health has deteriorated that I guess I wasn't expecting, you know, even two years ago he was, he was much more capable of doing things independently, then where now […] that that caught me off guard that there were these new things coming up and at one point they were coming thick and fast and that was overwhelming 'cause I, I just was like "Woah! Can I just [laughing] try and learn to deal with this first thing and how to approach it"'. (Barbara)

Unpredictability is a key challenge of caring for someone living with dementia, deep dips and small gains in cognition and physical health can lead to changes in support needs and so requires the carer to adjust, modify and flex accordingly. From a transitions perspective this illustrates how transitions are not linear – they are not progressing in one direction, rather in varying directions.

Here, early in the project Margaret is describing to me some ways she could tell her husband's dementia was changing:

> 'The disease progresses really quite fast you know, from month to month I can see a difference, you know, you're not really aware of it at the time, but when you think back a few weeks, you think "Oh he could do that then, but it's not doing it now". It was what we call our shower day, I can't shower him every day but I do try to as often as I can so I said "You can your finish your cup of tea and come on up and we'll get started' and he said "Where's up?", and I thought, "Oh dear, I mean upstairs!". Umm just odd wee things like that and then other times he's right on the ball, it's strange'. (Margaret)

Although not all changes had been negative since Margaret and I's previous interview, the positive changes seemed like the exception rather than the rule as Margaret explains after an urgent physiotherapy home visit was arranged following a series of falls:

> 'I don't have time to get used to the change before something else has happened, and in fact one went the other way in that the physio really helped his balance and walking and he is more steady now than he has been for a long time. So, he still uses his walker to go out and I've seen him wandering around the house without the stick now and he's quite steady on his feet, and that's an improvement'. (Margaret)

As time passed during the study, Margaret reflected more on the increasing intensity of her husband's symptoms and how her husband's increasing needs meant more support was likely to be needed soon. It feels especially pertinent that at this point routine becomes important to Margaret, and that change is a significant challenge:

> 'That's because he's deteriorated so much, it's such a fast, progressive, disease, condition, this one, yeah [sighs, clears throat] we're kind of getting close to the dates we were given, you know, for the end of life, uhm it's quite hard that, but I can see in the past month there's been a huge change in him and I can't really get used to any routine cos there is none, it keeps changing. Uh, you know looking back, yes, it's been a huge change and that's why we've had to get the care, and the next thing will be evening care too which I'm thinking about it, 'cause that's another area that is heavy going'. (Margaret)

Barbara and Margaret both expressed a great deal of sadness and of loss when speaking about the changes they were witnessing in their father and husband as a result of dementia. The disruption to day-to-day life was evident in the unpredictability of the disease, as was the realisation that the illness was progressing, and that adaptability was a constant requirement.

## HOMECARE PROVIDERS RESPONSIVENESS TO CHANGE

How, and when, homecare providers responded to changes in service requirements had a huge impact on the carer's experiences of beginning homecare. Barbara and Margaret experienced disorientation that was initiated by change caused by progression of dementia but then was echoed by homecare once adaptations in the service were requested. This left both Barbara and Margaret in the middle of a kind of reciprocal disorientation, a liminal state between the person they were caring for and the homecare provision.

Early in the project, Barbara spoke about attending a review meeting that was to discuss the homecare service in general and to request a change to the visit times because her father had been consistently sleeping until late afternoon**.** This was causing conflict with the homecare workers because they were only allotted a certain amount of time within a specified time slot for a visit, and Barbara felt a sense of responsibility to try and get her father up. This was also affecting Barbara's ability to work during the visit times. Barbara is describing here the difficulty of having the needs of her household recognised and yet unfilled because of constraints within the homecare system:

> 'We had a review last week about it and the request has been put in to have carers coming in for twelve, twelve-thirty, instead in the hope that that might be more umm effective. So, the carer company has said that they don't have the capacity to do that, so it's gone back up to umm, the commissioning team to look at another provider'. (Barbara)

It is clear just how difficult it is to continue with daily homecare visits that aren't working. Barbara begins to express that she is starting to feel that no homecare service might be better than a service that isn't working:

> 'But I had actually just in the last couple of days been thinking about saying, you know if [pause] if we can't get anybody in, can we just leave it for the time being until the provider does come back saying "Yes, we can do" it because in the meantime the carers are still coming in at ten-thirty'. (Barbara)

With Barbara expressing a sense of powerlessness or despondency toward the end of the interview:

> '…it's just, it just feels a little [searching for words] [sigh] I don't know what the right word is it just [pause] I had hoped to be in a different place than it is now, yeah. Gotta get on with what it is I guess, not much that's gonna change right now so. Yeah [clears throat]. That's it'. (Barbara)

When we returned to the conversation four weeks later, things were still on hold and Barbara seems to be describing a state of liminality:

> 'I'm still waiting for that [approval for changing hours] 'cause the err social worker's still on leave, yeah. Uhm, I have emailed her just to just to see if we can get things speed up because, it just, it, it, well kind of just feels very pointless at the moment. Still coming in at the ten-thirty so uhm, there's been one successful attempt actually to get him up and showered [pause] just feeling a little bit deflated'. (Barbara)

Six weeks later, some progress seemed to be on the horizon although Barbara was feeling increasingly despondent about the homecare package. The emotional strain of having visits daily at the wrong time is becoming evident and Barbara seems caught between the rigidity of the homecare provider and the unpredictable nature of dementia. In this quotation it is interesting to note that following a conversation with an external organisation they had stepped in to advocate on Barbara's behalf with Barbara's agreement. Barbara's exasperation with the situation continues to grow:

> 'Umm in terms of the, the care package, we've erm, I had a very quick catch up call with social work cos umm [voluntary agency] actually chased them up [sigh] because I was meant to have a, you know, the reports and everything and I spoke to them and they, they offered two different social workers so she phoned me towards the end of last week just uhm [pause] he basically just says that the request to get carers in for twelve-thirty had come back as uhm, the same company actually now having a position available, a spot available, for that time slot so she was going to follow that up'[…]'In the meantime they're still coming in at ten-thirty'. (Barbara)

When we returned for the final interview, after waiting for around twenty weeks for a change in visiting times Barbara was talking about how she and her family had been travelling in the previous month and when they returned things had changed again, with her father's routine, and with the homecare visit times:

> 'He actually started getting up, sort of normal time at about ten o'clock in the morning … he was consistently up at the same time every morning which is great. Uhm, so they just kept it at the, the, ten-thirty, and then when we returned it was suddenly changed to ten o'clock for some reason'. (Barbara)

Although at this point in the story things worked out well the sense of liminality – of being in between a service that didn't work and a service that might, of waiting for a conclusion to the problem and relying on a service that was not capable of being sufficiently responsive was worrying and immensely stressful for Barbara.

One time, however, homecare services were more responsive than anticipated. Margaret illustrates here how, like Barbara, having professional allies helped with accessing additional support:

> 'Hot news! Had the physio and OT [occupational therapy] people been out, yes, and they suggested a variety of things and they said that they asked for me to have support in the mornings from a carer, but said it wouldn't be for quite a while because they were very short staffed and it wouldn't happen, and on Monday there I got a phone call saying it's starting tomorrow, Tuesday, yesterday!'. (Margaret)

In Margaret's view she felt the input from the physiotherapist and occupational therapist had accelerated the beginning of additional homecare hours. However, Margaret goes on to explain that when she asked independently for support that would suit her husband's changing needs and allow her to remain as involved in his care as she wanted to be, the response of the homecare provider was dismissive. For Margaret it made her feel that the homecare provider had no real understanding of what her life as a carer was like. Margaret recounts the conversation with her local authority here, whilst reflecting on her thoughts at the time:

> 'I did speak to the social worker and say "Could I have somebody to come in at bedtime? Maybe once or twice a week?". "Uhh" he says, "Oh no!" he says, "My boss wouldn't buy that" he says, "You're either able to cope with putting him to bed or not" you know, "It's gotta be every night". I thought "You have never been a carer have you" umm 'cause you know yourself some days it all goes smoothly, and other days are a nightmare'. (Margaret)

The idea that homecare providers didn't understand what it meant to be a carer continued, demonstrating a rigidity in service provision that perpetuated liminal periods. Margaret describes feeling that it was her responsibility to push for homecare in a context where people did not recognise the anguish caused by her position whilst simultaneously feeling a need to 'put a brave face' on her experiences:

> '[long pause] It was a very difficult six months, particularly laterally before the care package came in. It seems always that you have to be in a crisis before you get really [the] support you need, so maybe if earlier I had been [pause] [sigh] not exaggerating but just really, letting them know what I was going through 'cause you do try to kind of not cover up, but you try and put a good face on and things at times [sigh]'. (Margaret)

Perpetual waiting, whilst faced with constant change, created a sense of powerlessness and helplessness for the carers, especially as the need for homecare services increased. This brought about feelings of despondency and at times despair that might have been eased by homecare providers had they been able to be more responsive.

Barbara's story illustrated a series of conversations in which the frustration and stress of being held in a liminal space are clear. Barbara's father's symptoms had continued to change and require adaptation whilst homecare services were not providing the support that was required because they were unable to respond to change efficiently. Barbara did not hold control or agency over either of these factors and as such was in a perpetual liminal space that she did not feel she had the resources or agency to bring to a conclusion.

Margaret experienced a long and difficult period of liminality during which she felt unable to continue in her caring role, but powerless to relinquish that role because the homecare that she needed, at the times that she needed it, was not available. This meant that Margaret was trapped in a situation that she felt unable to continue yet unable to escape. Similar to Barbara, Margaret also found that when allies such as other healthcare professionals or homecare workers advocated on her behalf, homecare services seemed to be more responsive and although in the short-term this was advantageous in getting results, it also reiterated that the carers were not being listened to by services.

# DISCUSSION

Although all transitions represent movement and change, the current study illustrates that for those who are caring for a person living with dementia in particular, the unceasing presence of change creates an uncomfortable liminal state. In an effort to better explain what the findings of the longitudinal phase of this study means for our understanding of non-normative transitions I introduce the concept of liminal dimensions of multiple and multidimensional transitions as an extension of the original MMT theory.

There is an uneasy sense of precarity in my study findings that I first attributed to the dynamic and fluid nature of transition itself, however, further reading and discussion led me to realise that the core concept that was central to my interpretation of the study findings is the concept of liminality (Turner, 1967, 1969; van Gennep, 1960). As with the previous conceptualisation of transitions as being multiple, multidimensional, and interconnected, so too are the liminalities of carers. Reflection upon the concept of liminality and how it fits with the complexities of MMT theory led to the mapping and then formation of five liminal domains. Here, I present the three domains most strongly linked with the longitudinal phase of the study.

## THREE LIMINAL DOMAINS OF MULTIPLE AND MULTIDIMENSIONAL TRANSITIONS

Rather than think of liminality as being a transient mid-section of moving from here-to-there, I am proposing here that multiple liminalities can be experienced at the same time and that these liminal domains can be closely linked to one another. Furthermore, these multiple liminalities can be interconnected with other liminalities and that they may persevere over very long periods of time. The liminal domains presented here are identity, agential, and temporal.

### Identity domain

Part of Barbara and Margaret's experiences around continuous change relate to their relational identity – the ways in which they felt their identities changed in relation to the person they cared for. Both participants speak of seeing their father and husband's behaviour change as a result of dementia, which is an example of how identities of both carer and cared for are not only in transition, but also at times liminal.

Transitions related to identity in the larger study include becoming a carer, becoming a wife/daughter/husband who provides care, developing anxious behaviour, becoming an advocate, taking on new responsibility, navigating a support system as a carer instead of as a professional, loss of professional identity, expectations of new identities and becoming a person who does not have agency in their life. The movement between these identities is not linear or sequential, and as such the liminal spaces related to identity were considerable. Both Barbara and Margaret have spoken with sadness of their identity becoming 'carer' first, before being a daughter or a wife – perhaps a legacy of a transition that began quite some time before the beginning of the study and is approaching its conclusion. It is not uncommon for people who are living with dementia to experience moments of lucidity in which they remember their relational ties with people who care for them, and other moments where these connections are forgotten. This can leave people providing care in a situation where their perceived identity might not match that of the person they care for.

Some of these identity transitions could have encompassed a transitional liminal phase, but many become perpetual (Gordon et al., 2020; Ybema et al., 2011) and not easily resolved: By partially inhabiting multiple identities, carers may find themselves in a state of involuntary anonymity.

### Agential domain

Particularly closely linked with the identity domain, the agential domain relates to changes in how much agency the carers had during the transitional period, and how the levels and types of agency changed. This is linked most closely with Barbara and Margaret's loss of power when homecare services did not respond to changing need, and to their lack of control over the symptoms of dementia that the person they cared for was experiencing.

According to liminality theory (Turner, 1969, pp. 94–130) when the person loses their place in the social world by being in-between identities, this reduces the person's social status and in turn causes a loss of agency. The effect of agency loss can then be seen in terms of the following transitions: Decrease in choice about how private spaces are used, reduced choice in decisions around how to use personal time, loss of control over the formation and maintenance of professional and personal relationships and decreasing independence of the carer. The agency-related transitions created multiple liminal spaces, some of which were inhabited simultaneously. For example, being an independent adult but also relying on networks and services in which you are neither an employee nor directly in receipt of a service means that carers do not have agency over how they use their time, space, and the services they receive, yet simultaneously are not able to leave the situation on which they, and the person they care for rely. A broader example is of Barbara having no agency over the changing routines and care needs of her father (due to dementia), whilst losing agency over her own time (due to homecare services) and not feeling that homecare services were listening to her, which leaves her in a liminal space in which she has a great deal of responsibility, but no power or control over conflicting aspects in her environment.

### Temporal domain

The temporal domain relates to time. How time can be planned, and who makes decisions over how time is used. Barbara in particular spent a great deal of time in a liminal space, whilst waiting for her father's homecare package to be adapted to meet his needs. Barbara and Margaret both spoke of the people they cared for in terms of their previous abilities and the ways in which those are changing. Both findings are representative of different types of liminality in the temporal domain.

Perhaps the most abstract domain, the temporal domain is concerned with the transitions and liminalities experienced through time. For each carer interviewed, identity was strongly linked with temporality and talk about who they used to be and who they are now in terms of their role. Margaret in particular was situated in a temporal liminality where she was not quite where she had been in terms of role and identity (as a wife, and professionally) and knew she could not stay where she was but did not yet know who she was becoming or in what timeframe.

Beside identity related temporal transitions, grief also transcends the temporal domain. When participants spoke of the past, often happy memories were remembered with sadness and grief, and the present was emotive in a similar way. There were, of course, moments of joy and laughter, but the experience of anticipatory grief, particularly where a person is living with dementia, is one that permeates the past, the present and the future, with little prediction of when the liminal phase may be concluded, and a new phase of grief might begin.

## THE POWERFUL INFLUENCE OF HOMECARE SERVICES

In looking back to the agential, identity and temporal liminal domains, I propose that during the early transitional phase of requesting or beginning a homecare package, aspects of homecare such as delayed assessments and reports, delays in responses and changes to care packages perpetuate the length of liminal periods. Furthermore, carers of people living with dementia are already unable to exercise agency over the trajectory of the illness and the experiences of the person they care for, so when homecare services are delayed, inconsistent or unreliable in ways that are also outside of the control of carers, this serves to emphasise their loss of agency, creating a cycle in which carers feel they are continuing to lose status and social capital, and as such continue to feel decreasing agency.

When agency is limited and liminality is prolonged, it is reasonable to intuit that the resultant marginalisation will create and perpetuate emotional distress. As such, homecare service providers should be cognizant that delays in response and action can be potentially harmful to carers. The study findings show that in order to be genuinely useful and indeed, not harmful, homecare services need to be ready to adapt by being responsive to quickly changing situations including crises and emergencies as opposed to being reactive to situations as and when they arise.

Services need to be consistent as to what is provided, when they are provided and who they are provided by, especially when a relationship between carers and occupational carers begins to develop. And they need to be stable: As carers continually adapt to the changes brought about by dementia, homecare services (combined with other networks of support) have an opportunity to provide a stable structure on which carers can theoretically rely. This stability was for the most part absent from the homecare services experienced by Barbara and Margaret, and notably the consistency and stability of the services appeared to decline as the hours in the homecare package increased.

In terms of recommendations for homecare service provision, it is essential that homecare providers do not underestimate their power to alleviate or perpetuate liminal spaces for carers. This could be done by focusing resources on minimising unnecessary liminality through providing consistent and reliable services, and training for staff to understand the pressures that informal carers can face.

### STUDY LIMITATIONS

The people who chose to participate in the study had to already be in a position to self-identify as a carer and were all recruited from the Join Dementia Research register. This potentially excluded many people who were considering making a request for homecare services but who did not choose to take on the term 'carer', as well as those who were not aware of the register. The implication of this limitation is that fewer people who might have been eligible to participate became aware of the study, and as such the study was able to recruit only a small number of participants.

The digitisation of the study, including online recruitment and data generation potentially excluded people who were either unable to have regular internet access or were not digitally literate. Although the purpose of recruitment was not to recruit large numbers of people, it would have been particularly interesting to hear about the experiences of people whose homecare experience was not supported by technology.

In future studies, I believe that a hybrid approach to recruitment such as using multiple digital resources to contact potential participants as well as taking a face-to-face approach in places such as carer groups or cafes might make research more accessible. Greater time allocation to the process of recruitment could support finding participants in studies that have very specific eligibility criteria.

### STUDY STRENGTHS

Taking a longitudinal approach with frequent interviews meant that more day-to-day experiences were captured as they were happening, rather than through a retrospective lens. This approach was a real strength of the study and would have benefited from an even longer period of data collection.

Within the larger study I was able to find and connect with a group of people who were experiencing a similar transitional phase in very different ways. Taking a transitions approach and applying MMT theory meant that I was able to bring depth and complexity to the analysis of carers' unique and yet unified experiences.

## CONCLUSIONS

Without doubt, Barbara and Margaret were on an emotionally and physically challenging journey during the times that I spoke with them. The transitions that they were experiencing were certainly multiple, multidimensional, complex, and interconnected, but moreover they were perpetual and liminal.

When I think of Barbara and Margaret's experiences, they could be described in terms of two separate rivers – one being dementia, and the other being homecare. These rivers sometimes flow concurrently and in unison, one supporting the other, but at other times they follow different trajectories that create tension in the space between one another, the liminal space inhabited by carers. This liminal space is one that is created by a loss of agency, choice and changes to relationships, and is maintained by constant change and the influence of homecare service providers.

Providing care and support to a person who has been diagnosed with dementia poses unique challenges from a transitions perspective. An unpredictable condition that does not follow a set trajectory or timeframe, dementia as a disease calls for more adaptability and flexibility than many other transitional states. Networks specifically including people with experience of dementia, and knowledgeable and accessible healthcare services, are essential in supporting carers and the people they care for during the multiple transitions of dementia care.

In returning to the title of this article, continuous change is a disruptive force in the lives of informal carers and those living with dementia in multiple ways. Dementia potentially affects the physical health, relationships, emotional and psychological wellbeing, social lives and living environment of both the person with a diagnosis, and the people around them. Equally, homecare services can be a disruptive force, but unlike dementia, homecare providers hold the power to minimise their own continuous change, and thus mediate the impact of change on carers. Although this minimisation and mediation would require a great deal of insight, compassionate design, and well-managed resources, it is not impossible.

> '...as my GP said, you know, [laugh] when I said to her that I really didn't want [husband] to go into care [...] she said, "That was before you knew what caring was and what it's about and what it involved". And she was right. I wouldn't have thought it was anything like this'. (Margaret, during our last interview, trying to put into words her experience as a carer).

## DATA ACCESSIBILITY STATEMENT

The data for this study will be deposited in the UK Data Service following completion of the PhD degree from which it was generated.

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The author has no competing interests to declare.

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## LAY SUMMARY

Five people who lived with someone with dementia as their main carer and were not receiving any more than six hours per week of paid homecare took part in this study. The aim of the study was to learn about the carers' experiences of the transition from being the main carer to sharing care with paid homecare workers.

Five carers completed one interview each in which they talked about their day to day lives, the difficult and enjoyable parts of being a carer, and how they felt about homecare beginning. Two of those carers then started to receive more homecare and completed a further seven interviews each over the following six months. The article explores the experiences of the two people who continued in the study for six months and found that the changing nature of dementia and the rigidity of homecare services caused carers to live in an uncomfortable and powerless state of multiple, interconnected types of liminality.

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