

Title: Extraordinary normalcy: home, relationships and identities in narratives of unpaid care

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Abstract

Based on audio diaries and narrative interviews with family carers, this paper suggests care can be understood as an experience of ‘extraordinary normalcy’, meaning that profound shifts in home, relationships and identities take place through care, yet these become part of the normalcy of family life. To maintain and understand a sense of normalcy, our participants utilise professional and technological interventions in the home and draw on notions of responsibility, reciprocity and role-reversal as frameworks for explaining why they continue to care, despite the challenges it brings. The paper considers how domestic activities performed in the home can both highlight the extraordinary aspects of care and help maintain the normalcy of the everyday. Extraordinary normalcy is a concept that problematises definitions of care that remove it from the relational and everyday, yet acknowledges the challenges people face when performing care. This paper contributes to a call for a narrative based development of social policy and makes recommendations for policy and practice based on the in-depth accounts of family carers.

Keywords: Home; care; responsibility; reciprocity; identities; family; extraordinary normalcy

Highlights

- Caring is an experience of extraordinary normalcy where profound shifts in home, relationships and identities are incorporated into the everyday.
- Caring for a family member with additional needs can result in a changing experience of home, relationships and identities.
- Successful professional or technological interventions in the home are those that facilitate routine and familiarity.
- Changes or interruption to domestic routines can highlight the challenges of caring and the progression of illness.
- Carers use notions of responsibility, reciprocity and role-reversal as an explanatory framework for caring for a family member.

Introduction

Carers UK (2014) estimate that 10.6 million people will have become unpaid carers for a friend or family member between 2014 and 2019. That the provision of unpaid care is a very common experience is reflected in the Care Act 2014, which places the needs of the carer on a par with the care recipient. Despite this attention to carers with policy, the construction of care as a uni-directional practice (from carer to care-recipient), with defined temporalities, relationships and activities, fails to encapsulate its complexities (Barnes, 2012). Consequently, the practical and emotional support needs of individuals providing care can be misunderstood (Molyneaux *et al*, 2011).

In this paper we suggest the simultaneous everyday-ness and complexities of caring can be understood as an experience of ‘extraordinary normalcy’. This concept expresses the profound changes in everyday spaces, relationships and identities that can occur when caring, whilst recognising that care is part of the ‘normality’ of everyday life. Working within a phenomenological framework, we develop this concept by drawing on a narrative interview and audio diary study into the lived experience of caring for a family member, contributing to Beresford’s (2016) call for a narrative approach to social policy. Before presenting this data, we detail some of the debates surrounding the discussion of caring within social policy, and the implications of this, then consider the UK care context.

The Care Act 2014 defines a ‘carer’ as ‘an adult who provides or intends to provide care for another adult’ (2014:10). In policy documents, ‘carer’ is often coupled with terms like ‘cared-for person’, demarcating providers and recipients of care (for example, Essex County Council 2015-2020 Carers Strategy). As well as enabling policy makers and practitioners to identify roles, responsibilities and needs, this terminology is utilised by organisations across Europe, campaigning for policy changes that benefit carers (Larkin and Milne, 2013; Molyneaux *et al*, 2011). However, such terminology is critiqued for

constructing caring relationships as uni-directional and divorced from a relational context (Beresford, 2012; Chattoo and Ahmad, 2008; Hughes *et al*, 2005; Molyneaux *et al*, 2011; Watson *et al*, 2004) and for creating barriers to emancipation and independence by marginalising ‘carers’ and ‘care-recipients’ (Hughes *et al*, 2005; Watson *et al*, 2004). Thinkers from the Disabled People’s Movement (DPM) argue that the terms invoke dependency (Beresford, 2012; Hughes *et al*, 2005), demarcating roles without recognising the multi-directional presence (or absence) of care. Molyneaux *et al* (2011) suggest that the actors are positioned ‘as taking opposing sides rather than as people sharing a relationship of care’ (2011:428). Importantly, they argue that a lack of identification with the term carer, something also identified by Lloyd (2006), means many individuals are resistant to or unaware of available support. Indeed, dis-identification with the term ‘carer’ was identified as a barrier to seeking support in a recent evaluation of Carer’s Assessments in Essex (Haines and Wetton, 2016).

The term ‘carer’, Molyneaux *et al* argue, is a ‘mark of bureaucracy, turning what is a normal human experience into an unnecessarily complex phenomenon’ (2011:422). Our data also suggests that the terminology formalises the experience of caring, removing it from everyday spaces and relationships. Following Molyneaux *et al*’s (2011) suggestion that relational terminology is preferable, we use the terms ‘carer’ and ‘care-recipient’ sparingly and for clarity. However, whilst care is absolutely a ‘normal’ human experience, human experience is also incredibly complex. Caring precipitates complex changes in relationships, spaces and identities that cannot be ignored. Through the concept of extraordinary normalcy we attend to the lived experience of care, taking seriously the immense shifts and challenges that can occur, whilst recognising how these are incorporated into the normality of everyday life. Extraordinary normalcy locates care in the everyday, as advocated by Molyneaux *et al*, (2011), and attends to the complexities of care often missing from social policy (Barnes,

2012). We keep the experience of caring in view, whilst challenging the carer/cared for binary. We contribute a focus on domestic activities as sites through which changing experiences of home, relationships and identities manifest, and identify the ways in which responsibility, reciprocity and role reversal provide explanatory frameworks that normalise caring.

Barnes (2012) suggests that reciprocity – providing care for those who care for us – offers carers a sense of autonomy, pride and purpose. We support and expand this by considering how responsibility, reciprocity and role-reversal operate in different ways to normalise the extraordinary. We use the term ‘responsibility’ to convey a sense given by participants that their familial roles (mother, husband, etc.) afford particular caring responsibilities. ‘Reciprocity’ expresses the understanding of caring as doing something for a family member that they had previously done for them. A particularly gendered manifestation of reciprocity emerged through the concept of role-reversal, where participants saw themselves as adopting the role of the person they care for (of becoming mother, or wife, for example). As will become apparent, these concepts provide explanatory frameworks that normalise the extraordinary aspect of care, incorporating it into the everyday.

Care in context

Successive UK governments, concerned with reducing state expenditure, have promoted home-based care. The marketization of older people’s care during the 1980s and 1990s saw a sharp reduction in state-funded residential care; by 2006/7 only 6% of care homes were council owned (Yeandle and Cass, 2014). Additionally, eligibility criteria for state-funded home care tightened, consequently, much home care is unpaid, or paid for privately (Yeandle et al, 2012; Yeandle and Cass, 2014). UK government spending cuts have impacted dramatically on social care provision (LGA, 2017). The period 2005/6-2012/13 saw significant reduction in recipients of state-funded care and expenditure on this care

(Fernandez, *et al.* 2013). An ageing population with complex and long-term conditions means demand for adult care is rising (National Audit Office, 2014), carers are absorbing the impact of reductions in state funding and provision (Yeandle and Cass, 2014). This reminds us that intimate, personal and familial practices are inextricably linked to government policy, ideology and provision (Dowling and Harvie, 2014; England and Dyck, 2011; Kroger and Yeandle, 2014).

The landscape of social care in the UK is characterised by state withdrawal from social care provision, the personalisation agenda (Power, 2013), and an emphasis on home care as preferable (England and Dyck, 2011), consequently, care is increasingly performed by friends and family in the home. Carers' needs are recognised under the 2014 Care Act, which states carers have a right to a needs assessment, which may result in support such as respite care, help with housework, adaptations to the home and emotional support. However, a recent survey found just half of all carers have been offered (28%) or asked for (22%) a carer's assessment since legislation came into force (Silman, 2016). Understanding the experience of caring is vital for a person-centred approach to policy development (Beresford, 2016), and ensuring carers receive support they are entitled to (Authors, 2011).

Home is a complex site; a memory, emotion, geographical location or physical building, loaded with meanings and emotions. Domestic activities – such as food provision – are laden with material, emotional and relational significance (Hamburg *et al.*, 2014; Rees *et al.*, 2010; Twigg *et al.*, 2011). When understood through the organising categories of public and private, home is often viewed as a private space of security and retreat from the 'threat' of public space (Gal, 2002; Harden, 2000). This romanticisation of home as a place of safety ignores the experience of it as risky, threatening, fearful (Author *et al.*, under review; Pain, 2006) or simply mundane (Douglas, 1991). Proximity to important places, objects and people can mean home care provides comfort and, for those providing end of life care (EOL), pride

at fulfilling a wish to die at home (Horsfall, 2017; Williams, 2004). However, Milligan *et al* (2016) argued that the capacity for such an emotionally charged experience to fundamentally change home has been overlooked in the idealisation of EOL home care. A discourse of home care as preferable in general also prevails (England and Dyck, 2011) and can over-simplify experiences of home, instilling impermeable boundaries between home and other spaces, rather than, as we explore here, viewing home as a place of change.

Whilst paid home care can afford power to care recipients, power dynamics shift as care needs change and the incorporation of features of the hospital and accommodation of healthcare professionals blurs the public/private boundary (Milligan, 2003:462). Professionals in the home challenge the notion of home as a private space and can reconfigure relationships between residents (England and Dyck, 2011). Familial dynamics are also reconfigured as care needs change. Increased need or sudden illness might require adult children and parents to live together, for example, marking a shift in familial, relational and specialised interactions and highlighting the interaction between time and space in experiences of care across the life-course. We consider temporalities of care in more detail elsewhere (Authors, 2015), however, data presented here illustrates how time and space are intimately connected. Care is shaped by relationships across the life-course, everyday temporal rhythms of the home and the trajectory of illness, thus supporting Bowlby's (2012) argument that 'caringscapes' need to be understood as both temporally and spatially organised..

As England and Dyck (2011:208) argue, home care blurs boundaries between 'caring for' and 'caring about', that is, the demarcation between 'task-orientated, physical labour' and 'relational, therapeutic emotional labour'. We illustrate how the 'caring for' that takes place in the home – the provision of food (Hamburg *et al*, 2014; Rees *et al*, 2010), performance of 'body work', or personal care (Chattoo and Ahmad, 2008; England and

Dyck, 2011) – are material, emotional and embodied, and cannot be extracted from familial relationships and spaces.

Method

To meet the aim of this paper, which is to propose that the lived experience of care is one of extraordinary normalcy, we draw on a study conducted for (name omitted), an independent organisation with a statutory role to gather views of health and care services through research and public engagement. The research sought to understand how unpaid care is experienced by Essex residents, a county in the south east of the UK, using narrative interviews and audio diaries with seven individuals providing care. This geographically bounded study is not representative, rather, we used methods that enable stories to be told in multiple forms and explored in depth, offering a novel means of capturing experiences of care. In contrast to research on EOL care (Horsfall et al, 2017), where accounts are retrospective and may become solidified, audio diaries capture the changeable nature of experience, alongside more ordered accounts in interviews.

From the outset we adopted a phenomenological approach concerned with participants' lived worlds, rather than categorising experience using fixed binaries or abstract theory (van Manen, 1990). Van Manen (1990) outlines four intersecting dimensions of lived experience – spatiality, relationality, corporeality and temporality. Each offer a lens for understanding lived experience and bring different aspects into sharper focus. Here we consider how experiences of care are spatially organised, drawing on a tradition that views space as essential to the formation and reproduction of social identities, themselves productive of material and symbolic spaces (Massey, 1999; Rose, 1993; Valentine, 2001). Recognition of the mutual constitution of space and identity challenges apparently impermeable spatial boundaries frequently employed in traditional geography (Rose, 1993). We draw upon this conceptualisation of space, relationships and identities to understand care

as a mobile, changeable, relational and affective practice (Barnes, 2012). A concern with the spatial emerged from the data, where it became apparent that home was central to the experience of caring, however, as will become evident, space intersects with time, relationships and emotions in various ways.

5-10 minutes audio diaries were completed daily by each participant across two-weeks. Audio diaries have been used to research various aspects of health and social care, including: breastfeeding (Williamson *et al.*, 2012); disability (Gibson *et al.*, 2013); dementia (Bartlett, 2011); healthcare professionals (Zwet *et al.*, 2014; Finnerty and Collington, 2013). They allow participants to record thoughts and feelings as they occur, to contribute when convenient, and to document the everyday across a discrete period (Williamson *et al.*, 2012). Participants are active in the construction of their account and can highlight issues of importance to them (Williamson *et al.*, 2012). Participants were asked to make recordings at any time, talking about thoughts, experiences and feelings relevant to caring. Deliberately sparse guidelines ensured participants directed content and form. Each participant used their diaries differently – some gave detailed accounts of their day, others reflected on key moments, or gave retrospective accounts – but all were equal in richness and quantity.

Narrative interviews took place a week after completion of the diaries and lasted 1-3 hours. Participants were asked ‘Can you tell me your story of being a carer’, with follow up questions based on their account (Wengraf and Chamberlayne, 2006). Participants had time to talk in a meaningful way, reflecting on caring across time and expanding upon diary recordings. Face-to-face interviews enable the interviewer to respond to non-verbal communication (Opdenakker, 2006) – particularly important for exploring emotive topics.

Participants were recruited through a carers organisation, restricting participation to individuals receiving support for themselves or a family member. Ethical considerations took

precedence when making recruitment decisions, ensuring support was available should participation cause distress. Snowball sampling resulted in diversity in terms of gender, age and relationship to family member. The group had commonality in that none were in paid employment, all lived with the care recipient (Alison, Debbie and Jen also lived with other family members) and all cared ‘24/7’. What might appear a heterogeneous sample, were in fact largely homogenous in their caring circumstances. Additionally, and largely reflecting the area’s demographic, all participants were white, six were British, and one, Edel, Irish.

Participant	Age	Family member	Family member age
Alison	55	Son – Sam	27
Debbie	64	Mother – Annabel	92
Fred	71	Wife – Helen	72
Edel	73	Husband – Martin	75
Jen	59	Son – Gareth	21
Harry	74	Wife – Jean	72
Simon	48	Mother – Barbara	81

Fig. 1. Participant details

The data was analysed by the first author using a thematic narrative approach (Riessman, 2008); narratives help us make sense of lived experience and explore it in its detail (Frank, 1997; van Manen, 1990). Following transcription, the data was read closely and repeatedly, attending to how participants described everyday experiences of caring and what themes emerged across the data. The details of the narratives were explored, taking into account significant spaces, people, thoughts and feelings. In accordance with phenomenological and narrative approaches, the analysis presents in-depth discussion of aspects of participant narratives, that were illustrative of the key themes. We focus here on shifting experiences of home, relationships and identities in narratives of care.

The following analysis explores the experience of care as one of extraordinary normalcy, a concept that emerged from the data. We consider firstly the profound changes in homes, relationships and identities that occur when caring. Then discuss how changes are incorporated into the normalcy of family life through the performance of domestic tasks. Finally, we argue that responsibility, reciprocity and role-reversal are expressed through the domestic and offer an explanatory framework for caring.

Extraordinary, everyday spaces.

Home is a site of movement and activity continually reshaped by material, relational and embodied activities. Experiences of home change across the care trajectory. Debbie and Simon, both caring for their mothers who have dementia, demonstrate how homes can become alien or extraordinary as illness progresses and care needs change.

When Simon's mother, Barbara, became ill, he moved into her home. She was increasingly dependent upon him and anxious in his absence; Simon could not leave a room without Barbara calling for him. He had to sleep on her bedroom floor because: 'she wants to hold my hand all night. So, if she wakes up and I'm not holding her hand then she'll wake me up just to hold her hand' (interview). Even when sleeping, Barbara's needs shape Simon's movement, activity, temporal and spatial experience of home. Here Simon describes how his movement around the home, as well as his access to outside space, is negotiated through his mother's anxiety:

It took me most of the afternoon to get the washing up from lunchtime done, because every time I went into the kitchen she would want me back in the lounge with her. So that's just one example. But there's, there's other examples as well. For example, I wasn't able to put the rubbish out today, 'cause she didn't want me to go outside. Erm, not even to put the rubbish out. (audio diary)

Whilst Simon's account echoes Chattoo and Ahmad's (2007) description of carers as 'trapped in the private sphere' (2007:556), his experience of home is more than just being trapped, but one of the home and his movement around it being altered through the demands of care. Simon's very material, spatial and temporal relationship to the home is altered through his mother's increasing reliance upon him. As we shall see, domestic activities and routines, such as washing up and putting the rubbish out, can provide a sense of normalcy in familiar spaces. When this is disrupted, as Simon describes, the home can become an extraordinary space in which familiar routines and ways of relating become part of the mechanisms that leave carers feeling 'trapped'. Simon's movement around the home is mapped onto his mother's anxiety, the home is marked by illness and this alters his experience of it. It is important to note here that, just as the experience of space is not static, neither are the emotions that emerge through caring. Simon expressed a range of emotions throughout his interviews and diaries – loss, sadness, love, care, frustration – but also emphasised the enjoyment he took from caring for Barbara and was keen that he was not represented as resentful of her. As we later discuss, this was often expressed through a notion of reciprocity.

Debbie also illustrates how home is reshaped through care, particularly how progression of illness and changing need is mapped onto the home. In a diary entry, Debbie explains that she and her husband Steve had been delayed on a journey home as dusk set in. Debbie telephoned her mother Annabel, who was alone at home, and found she was in the dark, unable to turn the lights on. Debbie directed Annabel to light switches over the phone, recounting that 'it was very difficult because she had to keep putting the phone down and going away and then coming back to tell me that she hadn't been able to find the light switches'. A timer switch may have provided a relatively simple material solution to this problem, but what is significant here is that the progression of Annabel's illness becomes

apparent to Debbie through Annabel's changing knowledge of the home and her movement around it.

Further, Annabel's changing experience of the home is formative of Debbie's emotional experience of caring and her own sense of whether she can sustain other relationships and activities. She says:

The opportunity this morning was to go with Steve and spend the day with Steve, which is something I haven't done for I can't remember how long, and it's really, really frustrating and upsetting that I can't do that and leave Mum knowing that she's secure. (Audio diary)

Through Annabel's deteriorating knowledge and understanding of functions in the home, Debbie begins to feel that home is no longer a secure space for her mother to be alone in, generating feelings of frustration. Debbie illustrates how changing interactions with or knowledge of familiar environments can make the home unfamiliar or unknowable. As home becomes more difficult to navigate for Annabel, Debbie's experience of it changes, demonstrating how home is relationally formed.

Debbie and Simon illustrate the intimate connection and leaky boundaries of home, relationships and identity. Each impact upon and reshape the other in complex and intricate ways. The progression and demands of their mothers' illnesses precipitate changing experiences of everyday spaces. Homes that were once sites of easy movement, or security, are viewed and experienced differently across time and place, these changes are often expressed through domestic routines or changing movements through familiar spaces.

When caring, the home is not just one thing, whether that is restrictive, or insecure, but is a changeable site. Daily care practice may be repetitive – Alison, for example, referred in her diary to 'the same old boring routine' of caring for her son – however the material and

emotional experience of routine shifts and changes, resulting in a changing relationship to the home.

Creating normalcy through the domestic.

When activities or interaction with domestic spaces become more difficult for either family member, this can create a sense of home as restrictive, unsafe, or unfamiliar. However, consistent and familiar domestic routines can provide a sense of normalcy in the home and means of managing relational shifts that occur when someone requires additional care. In examples that follow, creating normalcy and familiarity requires either professional or technological interventions in the home. In contrast to Simon and Debbie's experiences, Edel and Harry's accounts illustrate how interventions can create a sense of normalcy in familiar spaces, relationships and identities: here change maintains the familiar.

Edel, caring for her husband Martin who has a long-term physical disability, discussed her experience of paid care in the home. As argued by Milligan (2004), paid home care blurs the private/public boundary; the home as another's workspace highlights that home is never entirely private. Edel discussed the impact of the late arrival of paid carers on her domestic routine:

This morning I got up round about eight o'clock and got a cup of tea ready and gave my husband his breakfast. And I thought I'd wait until the carers had been to have my shower. But at twenty to eleven I had to go up and have my shower anyway. And it meant leaving the front door open on the catch, which I don't like doing. (audio diary)

As Martin cannot move to open the door, Edel had to either wait for the paid carer's arrival or leave the door on the latch whilst she showered, when they were late she chose the latter. It is instances like this, that are out of place in, or disruptive of, daily routines, that transform the emotional experience of home. At this point, home as a space of

material and symbolic security (England and Dyck, 2011) is threatened for Edel as time and space are reorganised to accommodate another's workspace and home no longer feels secure. In contrast, when paid care in the home is reliable and familiar the emotional experience of home changes and familiar domestic routines can be maintained. Here Edel discusses the arrival of a carer paid for privately:

[The carer] comes at the same time every Monday. She comes at 9:30. So it meant I could take my time getting up, make a cup of tea, give my husband his breakfast and I waited 'til she got here to go up in the shower, which means I could have a nice relaxed shower. (Audio diary)

The intervention of paid care means Edel experiences home as more than a caring or work space. This contrasts with England and Dyck's (2011) suggestion that as paid care in the home increases, the occupant's sense of control over the space dissipates. When known paid carers arrive at the same time every week, they become a familiar part of Edel's routine and their presence is woven into the fabric of daily life. What might be considered an extraordinary event – having a professional in the home – enables Edel to retain a sense of normalcy in her morning routine and of home as a place of relaxation.

The symbolism and affect of home, becoming either a site of insecurity or relaxation, is reworked as it interacts with the temporality of paid care. The interruption and re-organisation of home through the presence of professionals was a key concern for our participants, but Edel's account demonstrates it is not necessarily the increased presence of professionals in the home, but the regularity and reliability of that presence, that shapes the experience of it.

Edel's account signals the interaction between the demands placed on paid carers with the needs of clients. As England and Dyck (2011) discuss, many paid carers are under pressure to work within strict time limits, making it difficult for their presence

in the home to be one that facilitates relaxation and care, creating instead a sense of disempowerment. Well-timed interventions can offer a sense of normalcy that allows occupants to experience home as familiar and secure. Recognition of the importance of space, and how the presence of professionals can alter emotional experiences of home, is crucial in supporting carers and alleviating feelings of isolation, stress and anxiety (Brown and Mulley, 1997; Carers UK, 2014; Girgis et al., 2013; Maher and Green, 2002).

Other interventions that helped create normalcy were subtler, yet similarly facilitated everyday routines, activities and sense of security. Harry illustrates this through his discussion of keeping pigeons in a pigeon loft at the home he shares with his wife Jean, who has dementia. The loft provided Harry with a space to express emotion when Jean was diagnosed; during his interview he said: 'I just went down there and cried my eyes out... 'cause I just couldn't believe what was happening'. Caring for his pigeons was an activity Harry, with the encouragement of his children, wanted to continue, despite Jean's increasing support needs. Continuing with his hobby, which afforded Harry a space to process his emotions, required alterations to the home to ensure Jean was secure and cared for in his absence. Harry installed alarms in the home and placed a tracker in Jean's handbag in case she, as he described it, 'did a bunk' whilst he was absent. Technological interventions enabled Harry to extend care to Jean when he was not present and to continue with a hobby he loved.

For all participants, making space for, or holding onto other aspects of their identity was challenging and required the manipulation and management of the spaces in which they care. Having a hobby, pursuing further education, or seeing friends are activities that are worked around care and into the home. Consequently, alternative

identities of, for example, student or friend, are constantly under threat, but also a vital means of maintaining a sense of self and managing the emotional pressures of caring.

In both Edel and Harry's accounts, the maintenance of familiar activities and routine required change and intervention in the home. Whilst some interventions can be disempowering (England and Dyck, 2011; Milligan, 2003), when professional or technological interventions are woven into the fabric of home and become familiar, reliable, or unobtrusive, they help maintain everyday routines and activities. In contrast to Simon and Debbie's experiences of a changing relationship to home becoming apparent through disrupted routines, change through the form of interventions assist Edel and Harry in creating a sense of normalcy and familiarity in their everyday.

Responsibility, reciprocity and role-reversal in maintaining extraordinary normalcy

Domestic activities can be moments where the extraordinary becomes apparent, but also through which normalcy can be maintained. In this section, we consider how domestic activities fulfil and enact a sense of responsibility, reciprocity and role-reversal for some participants and offer a framework for explaining why they care, no matter how challenging. For those who draw on them, these explanatory frameworks can foreground familial relationships, positioning the often-extraordinary tasks they perform as a 'normal' part of these relationships. However, these frameworks are inadequate for participants who anticipated changes in their domestic routines across the life course, for example, following retirement.

Across the data, cooking, cleaning and 'body-work' (Twigg, 2011) – washing and personal care – featured heavily, reflecting its prominence elsewhere (Chattoo and Ahmed, 2007; England and Dyck, 2011). The diaries gave a striking sense of the dominance of such activities in daily routines, and how these routines are embedded in the home. For example, most of Fred's diary entries began with an account of checking his wife, Helen, is washed

and dressed each morning, and how this checking might result in returning to the bedroom to help her change out of pyjamas she is still wearing under her clothes. Fred's account illustrates how 'body-work' (Twigg, 2011) is repetitive and embedded in place, dictating movement around the home.

Fred uses a framework of familial responsibility to locate repetitive or difficult aspects of care within the normalcy of family life, illustrated through his account of cooking for Helen. Fred's emotional experience of care, as frustrating but also an expression of love and intimacy, was manifest through food provision. He took great care to provide inviting and nutritious food for Helen and her reluctance to eat frustrated him: 'I'm fed up trying to do my best to feed her nicely and this constant rejection' (audio diary). However, food was also a way of creating intimacy and repairing moments of tension; later in the diary Fred says: 'I've given her a Fisherman's Friend and tucked into bed...and I say, 'I'm sorry I lost my temper'... 'I love you, I will look after you...'. The provision of food is laden with symbolism and emotion (Rees et al, 2010) and is a material and embodied site through which emotions emerge. When Fred gives Jean a cough sweet and tells her he loves her, it brings relational identities 'husband' and 'wife' to the fore, superseding 'carer' and 'care-recipient' and emphasising spousal responsibility to love and care. This fleeting moment, which emphasises spousal responsibility, reinstates a sense of relational normalcy, following a highly emotive day where the extraordinary aspect of care was highlighted through Jean's repeated refusal of food. Jen similarly describes the care she performs for her son Gareth, who has autism, in familial terms, emphasising her maternal responsibility to care, despite the restrictions she experiences:

I'm his mother. Mothers care. I don't need to be- I mean, I know I'm his carer, but then, as I said, I cared for my daughters as well. I don't see myself as Gareth's carer.

I'm, I'm his... I'm just really doing what I should do. And although it's restricted my life to a certain extent, you know, it's just what you do (Interview)

These accounts of care as a familial responsibility encompass both 'caring for' and 'caring about' (England and Dyck, 2011), whereby all aspects of care (emotional, physical, financial, material) are familial, relational practices. Like many family carers (Lloyd, 2006), Jen rejects the label 'carer' and prioritises familial positionings. This, however, carries limitations when interacting with professionals. As Alison, also caring for her son, explains, she adopts the identity 'carer' strategically, when 'being mother isn't getting me anywhere' (interview). The experience of familial positionings not carrying purchase with professionals was common and indicates a need for the expertise and knowledge developed by family members, and the 'caring for' and 'caring about' they perform, to be fully recognised.

Like Fred, both Jen and Alison locate care within a framework of familial responsibility to manage challenging or restrictive moments. These accounts of responsibility came from participants for whom caring meant a continuation of emotional and domestic labour – as Alison comments 'mother's care', and throughout his marriage Fred had always cared for his wife, who had a history of mental health problems. In other accounts, shifts in domestic responsibility occurred following the onset of illness that resulted in the person who usually performed domestic tasks being unable to do so. Here, concepts of reciprocity and role-reversal allowed participants to see caring as a way of doing for their family member what they had done for them and so normalised domestic and relational change. Reciprocity embeds care in pre-existing relationships, as Harry and Simon illustrate:

'Cause, you know, she says, 'I love you', and she said, 'You're super. I don't know what I'd do without you'. So I said, 'Well we're married and that's it. You'd look after me, I look after you, until death do us part'. Then we have a cuddle and then everything's ok (Harry, interview)

But to reiterate really that my mum is my mother. She looked after and cared for me all those years and I therefore feel and want to look after her the best that I possibly can, for as long as I possibly can. And that is indeed what I intend to do.
(Simon, interview)

Harry and Simon demonstrate a commitment to reciprocal care across the life-course, an explanation of care seen elsewhere (Barnes, 2012; Chattoo and Ahmad, 2007). Barnes (2012) suggests reciprocity can offer carers autonomy, pride and purpose and this is certainly reflected in Harry and Simon's accounts. Developing Barnes' argument, we suggest that reciprocal care requires developing a new relationship to and interaction with the home as familial relationships and identities are renegotiated through domestic activities.

Harry, for example, recalls being taught to cook and clean by his daughter and paid carers, expressing his pride in new skills: 'I cooked my first Christmas cake this year. I made it and it turned out well...it turned out better than hers [the paid carer] actually!' (interview). Through performing domestic tasks Jean once took responsibility for, Harry started to think of himself as her carer: 'I suddenly realised, "Oh crikey, I'm a carer. I'm looking after her now, not her looking after me or we're looking after one and other"' (interview). Shifts in identity are intimately connected to a changing relationship to the home and domestic, emotional and relational activities that take place there.

Reflecting the oft naturalisation of care for women (Watson et al, 2004) and the gendered division of domestic and emotional labour (Moreno-Colom, 2017), Harry and Simon both gender their care practices through role-reversal. Harry, when giving an account of learning to cook and clean, says: 'I'm the housewife, so it's reversed' and, reflecting on the emotional and practical support Barbara requires, Simon says 'I'm having to be the...the

father figure, or mother figure...because she's very much the child'. Simon corrects 'father figure' to 'mother figure' here, suggesting that 'father' cannot fully accommodate care, yet 'mother' can. Harry and Simon illustrate how, even if relational shifts occur and new roles are adopted, a gendered language of care is still used to define and express those relationships, particularly when discussing domestic tasks. This gendered nature of domestic labour is often missing from policy discussions (Watson *et al.*, 2004).

However, whilst Harry and Simon utilise gendered language to describe relational shifts, they do accommodate their caring role within their husband/son identities. Through narratives of reciprocal care, Harry and Simon accept this shift as part of their role, both commenting that they are doing for their wife/mother what they had done for them. Harry and Simon view care as much a part of being husband/son as wife/mother, the gendered terms they use operate as shorthand for expressing relational shifts, rather than suggesting care is innately gendered. Giving an account of care as reciprocal and relational allows Harry and Simon to incorporate care into their pre-existing familial roles, whilst also blurring the gendered boundary they instil in their discussion of domestic tasks. Ahmet (under review) also found that many men saw care as a part of their familial role, rather than caring as a feminised role, suggesting there is more to be understood about the specific experience of male carers.

Through domestic tasks performed in the home both Harry and Simon experience a changing interaction with the home, shifts in their relationships, and the sense of their own role and responsibilities as husband or son. However, these changes are not static; notions of reciprocity allow Simon to manage the shift in relationship dynamics by viewing them as movable and reaffirming mother and son identities whenever possible:

She has moments when she is perfectly okay and you would think there was nothing wrong. So, from that point of view I try and keep the mother and son

relationship there because when she's like that I try to become the son again...And let her be mother again (Simon, interview)

Similarly, Harry reflects on the moments of 'normalcy' that made him decide against residential care for Jean:

She's quite, she was quite capable of going out for a walk and coming back, all that sort of thing. And I thought, 'No, I can't have that. I can't have my loved one go there whilst I'm here on my own all the time' (Interview)

Home care offers Simon and Harry the opportunity to retain aspects of their pre-illness relationships with their mother and wife. The continuation of these roles is desired to provide a sense of normalcy and continuity following illness (England and Dyck, 2011; Horsfall et al, 2017). For explanatory frameworks to be helpful they need to accommodate the dynamic and mobile dimensions of care, making space for mutual care and shifts in power, dependency and familial roles. Responsibility, reciprocity and role-reversal recognise mutual care across the life-course, even when most caring tasks might be performed by one person. It is crucial that Simon, for example, can make space for his mother to care for him, even if these moments lessen as her illness progresses.

As suggested, the framework of reciprocal care and role-reversal was inadequate for participants who found that caring responsibilities prevented desired shifts in domestic roles. Here, Edel reflects on how she had anticipated spending her retirement:

I just feel the same sort of, more or less, a housekeeper, sort of maid doing everything at...I was looking forward to retirement when we could do things

between us, but unfortunately it hasn't transpired. I have to do everything myself.

(Audio diary)

Edel also genders the care role, but unlike Harry and Simon, this do not appear movable. In contrast to England and Dyck's (2011) suggestion that caring can facilitate lifestyle changes, for Edel, caring for Martin extends and reinforces the roles she adopted throughout their marriage and this lack of change is disappointing. The differences between Harry and Simon, and Edel's narrative illustrate that the emotional experience of care, and so support needs that individuals have, can only be understood in the context of existing relationships, hopes and expectations, and experience of care across the life course.

Conclusions

The concept of extraordinary normalcy captures the profound shifts that take place in everyday spaces, relationships and identities when caring for a family member, yet recognising how these are part of the everyday normalcy of family life. This concept contributes to the critiques of the terminology of care embedded in social policy that divorces it from the everyday (Barnes, 2012), yet recognises and attends to the many challenges carers can face (Arksey and Hirst, 2005; Carduff et al., 2014). Home is a key site through which the extraordinary normalcy of care is expressed, shaped, manifest and, often with interventions, maintained. The emotional and physical demands of caring are well documented (Arksey and Hirst, 2005; Carduff et al., 2014) and it is recognised that space is formative of experience (Milligan, 2003; Milligan and Wiles, 2010; Horsfall, 2017) and so, to support carers, it is crucial spaces of care are taken seriously. Our participants' accounts demonstrate that home, relationships and identities are continually reshaped through care and here we make suggestions for policy and practice based on their accounts.

Through a close reading of participants' narratives, we trace how extraordinary aspects of care become apparent through the domestic; as routines are interrupted and relational shifts occur, changes in need shape movement around, and emotional experience of, home. When domestic routines are familiar, a sense of normalcy in the home can be achieved, even amidst these changes. This is often realised through successful interventions in the home, which may include professional support, or technological assistance. Therefore, our first recommendation for policy development is for carers assessments to identify how interventions can work within the rhythms of household routines, to facilitate normalcy, rather than emphasise the extraordinary. This requires an understanding of the relational, emotional, spatial and temporal dimensions of everyday life and consideration of how change can be facilitated when required, and familiarity maintained when desired.

Responsibility, reciprocity and role-reversal emerged as explanatory frameworks for familial care. Whilst narratives of reciprocity have been identified in other studies (Barnes, 2012; Chattoo and Ahmad, 2007), our research expands this through its focus on the domestic as an expression of reciprocity and suggests that reciprocity, responsibility, and role-reversal are distinct notions that work differently for different people. When participants saw caring as a continuation of a role they had always occupied, notions of responsibility brought familial and relational identities to the fore, emphasising, for example, care as an aspect as maternal responsibility, rather than something extraordinary. This offers a framework for continuing to care for participants who had not seen a shift in their role. For people who had experienced change and were undertaking domestic and emotional labour that had previously been performed (predominantly) by the person they were now caring for, notions of reciprocity and role-reversal explained this shift as a process of giving back to that person. This framework explains the continuation of care, even when it is difficult or restrictive. For individuals who anticipated or desired a shift in domestic or emotional labour across the life-

course, following retirement or upon children leaving home, for example, these explanatory frameworks appear to be inadequate and do not relieve feelings of frustration or disappointment.

We suggest that the experience of caring for a family member can only be understood, and so effective support provided, in the context of biographies, relationships and expectations across the life course. Carer assessments need to consider how someone explains and understands the care they perform and support should be provided on these terms. This should include discussion around terminology (how does the term 'carer' feel?) and recognition of familial knowledge, ensuring that the term 'carer' does not carry more weight than, for example, 'mother'. Whilst daily care tasks might be unchanging, the affective, relational and material experience of them is highly changeable and attending to how individuals talk about care offers insight into these changes and ways of managing them.

Our methodological choices enabled us to explore multi-layered accounts of care in depth and build on the use of narrative methods and audio diaries to research health and social care (Bartlett, 2011; Finnerty and Collington, 2013; Gibson *et al.*, 2013; Williamson *et al.*, 2012; Zwet *et al.*, 2014). In doing so we contribute to Beresford's (2016) call for approaches that bring experience and narrative to the centre of policy development. Caring is not a static experience, it is relational, affective, spatial and temporal. Our participants' accounts of care illustrate that policy decisions are felt through the home and shape relationships and identities and this is a vital consideration for understanding experience and providing support.

There are also limitations to our approach that need to be acknowledged. Although there was diversity in their relationships to the person they were caring for, the participant group is largely homogenous; all lived with their family member, none were in paid

employment and all white and majority British. This group do not represent the diverse care arrangements, relationships and contexts in which many individuals care. Spaces of care might be experienced very differently for people not living with the person/s they are caring for. Whilst this means our findings are not generalisable, it also illustrates what narrative approaches to social policy (Beresford, 2016) demand – that the particular biographies, relationships, emotions and identities are taken into account when developing and thinking about the impact of policy. As Molyneaux *et al* (2011) observe, understandings and terminologies of care are culturally specific and there is scope for further analysis that explicitly considers the cultural manifestations of care apparent in participant’s narratives. Ahmet *et al* (under review) argue for an intersectional approach to understanding care, one that accounts for gender and ethnicity, and this is something that could be developed here, particularly important because of the tendency for whiteness to be made invisible and to go unnoticed (Ahmed, 2007). Contributing to the homogeneity of the group is the decision we made to recruit through a carer organisation commissioned by the local authority, meaning that all participants were accessing some form of service. The vast majority of individuals providing care are unknown to local authorities and other professionals.

Finally, whilst we intend here to advocate for an approach to understanding care that moves beyond the ‘normative’ understanding often found in social policy (Barnes, 2012), encapsulated by the carer/cared for binary, in speaking only to individuals providing care, we risk reproducing this binary. Additionally, our focus on home risks defining care as a series of practical tasks such as dressing, washing and food provision. Alternative methods that gather the experiences of a range of people involved in the care relationship could address this limitation, yet, by using narrative methods to hear the accounts of people defined as ‘carers’ we have been able to illustrate how this role is understood as embedded in family, relationships, emotional and everyday spaces. Whilst our choice of methods always carries

the risk of reinforcing binaries, we hope that the voices of the participants illustrate how the carer/care-recipient binary does not fully encapsulate the experience of care and how practical tasks, such as the provision of food, are always also relational, biographical and emotional.

Care as practice highlights how the 'normative concept' of care used in social policy – with defined temporalities, relationships and activities – cannot fully encompass its complexities (Barnes, 2012:6). Phenomenological and narrative approaches offer a more expansive notion of care, placing it in the context of relationships, emotions and identities (Barnes, 2012; Beresford, 2016; Frank, 1997). We reject understandings of care, often found in policy (Molyneaux *et al*, 2011), that remove it from the everyday, but attend to its challenges, viewing it as both everyday and extraordinary. We agree that care roles exceed the limits by which they are described in policy documents (Barnes, 2012; Bowlby, 2012; England and Dyck, 2011), whilst extending this work through the concept of extraordinary normalcy and the focus on home. Extraordinary normalcy expresses how everyday experiences profoundly reshape identity, home and relationships, exposing their leaky boundaries. It also challenges binary understandings of caring relationships, approaching care as a spatialised practice performed through moments and interactions, shaped by personal histories and biographies.

References

- Ahmed, S., 2007. A phenomenology of whiteness. *Feminist theory*, 8(2), 149-168.
- Ahmet, A., under review. Understanding Narratives of Care and Caring: Intersectional and Policy Considerations among Black Minority Ethnic Groups in England and Wales. *Ethnicity and Health*.
- Andrews, M., Squire, C. and Tamboukou, M. eds., 2013. *Doing narrative research*. Sage: London.
- Arksey, H., & Hirst, M., 2005. Unpaid carers' access to and use of primary care services. *Primary Health Care Research and Development*, 6(2), 101–116.
- Barnes, M., 2012. *Care in everyday life: An ethic of care in practice*. Policy Press, Bristol
- Bartlett, R., 2012. Modifying the diary interview method to research the lives of people with dementia. *Qualitative Health Research*, 22(12), pp.1717-1726.
- Beresford, P., 2012. From 'vulnerable' to vanguard: challenging the Coalition. *Soundings*, 50(50), 46-57.
- Beresford, P., 2016. *All Our Welfare: Participatory Social Policy*. Policy Press, Bristol.
- Bowlby, S., 2012. Recognising the Time—Space Dimensions of Care: Caringscapes and Carescapes. *Environment and Planning A*, 44(9), 2101-2118.
- Carduff, E., Finucane, A., Kendall, M., Jarvis, A., Harrison, N., Greenacre, J., & Murray, S. A., 2014. Understanding the barriers to identifying carers of people with advanced illness in primary care: triangulating three data sources. *BMC family practice*, 15(1), 48.

Carers UK., 2014. Need to Know; Transitions in and out of caring: the information challenge. Social Policy Research Unit, University of York. Available: <https://www.carersuk.org/for-professionals/policy/policy-library/need-to-know> (Last accessed 9th February 2018)

Chattoo, S., and Ahmad, W.I., 2008. The moral economy of selfhood and caring: Negotiating boundaries of personal care as embodied moral practice. *Sociology of Health & Illness*, 30(4), 550-564.

Douglas, M., 1991. The idea of a home: A kind of space. *Social Research*, 58(1): 287-307

Dowling, E., & Harvie, D., 2014. Harnessing the social: State, crisis and (Big) society. *Sociology*, 48(5), pp. 869-886.

England, K., & Dyck, I. 2011. Managing the body work of home care. *Sociology of health & illness*, 33(2), 206-219.

Fernandez, J., Snell, T., Wistow, G., 2013. Changes in the Patterns of Social Care Provision in England: 2005/6 to 2012/13. PSSRU Discussion Paper 2867.

Finnerty, G. and Collington, V., 2013. Practical coaching by mentors: Student midwives' perceptions. *Nurse education in practice*, 13(6), pp.573-577.

Frank, A.W., 1997. *The Wounded Storyteller: Body, Illness, and Ethics*. University of Chicago Press.

Gal, S., 2002. A semiotics of the public/private distinction. *Differences: a journal of feminist cultural studies*, 13(1), 77-95.

Gibson, B.E., Mistry, B., Smith, B., Yoshida, K.K., Abbott, D., Lindsay, S. and Hamdani, Y., 2013. The integrated use of audio diaries, photography, and interviews in research with disabled young men. *International journal of qualitative methods*, 12(1), pp.382-402.

Girgis, A., Lambert, S., Johnson, C., Waller, A., and Currow, D., 2013. Physical, psychosocial, relationship, and economic burden of caring for people with cancer: a review. *Journal of Oncology Practice*, 9(4), 197–202.

Grosz, E. 1994. *Volatile Bodies: Towards a Corporeal Feminism*. Indiana University Press, Bloomington.

Haines, S and Wetton, Y., 2016. Carer's Assessments in Essex: what do carers say? Healthwatch Essex. Available at: <https://www.healthwatchessex.org.uk/wp-content/uploads/2016/01/Carers-Assessments-in-Essex-FINALv2.pdf>

Hamburg, M.E., Finkenauer, C. and Schuengel, C., 2014. Food for love: the role of food offering in empathic emotion regulation. *Frontiers in psychology*, 5, 32.

Harden, J., 2000. There's no place like home: The public/private distinction in children's theorizing of risk and safety. *Childhood*, 7(1), 43-59.

Horsfall, D., Leonard, R., Rosenberg, J.P. and Noonan, K., 2017. Home as a place of caring and wellbeing? A qualitative study of informal carers and caring networks lived experiences of providing in-home end-of-life care. *Health & place*, 46, 58-64.

Hughes, B., McKie, L., Hopkins, D., & Watson, N., 2005. Love's labours lost? Feminism, the disabled people's movement and an ethic of care. *Sociology*, 39(2), 259-275.

Lloyd, L., 2006. Call us carers: Limitations and risks in campaigning for recognition and exclusivity. *Critical Social Policy*, 26(4), pp.945-960.

Local Government Association., 2017. *Adult social care funding: 2017 state of the nation report*, ref 1.69. Available:

<https://www.local.gov.uk/sites/default/files/documents/1.69%20Adult%20social%20care%20>

funding-%202017%20state%20of%20the%20nation_07_WEB.pdf (last accessed 09 February 2018).

Legislation.gov.uk. (2014). *Care Act 2014*. [online] Available at:

<http://www.legislation.gov.uk/ukpga/2014/23/contents/enacted> [Accessed 6 September 2017].

Massey, D., 1999. Space of Politics. In Massey, D., Allen, J., Sarre, P (Eds), *Human Geography Today*. Polity Press, Cambridge, pp. 279-294.

Milligan, C., 2003. Location or dis-location? Towards a conceptualization of people and place in the care-giving experience. *Social & Cultural Geography*, 4(4), 455-470.

Milligan, C., & Wiles, J., 2010. Landscapes of care. *Progress in Human Geography*, 34(6), 736-754.

Milligan, C., Turner, M., Blake, S., Brearley, S., Seamark, D., Thomas, C., Wang, X. and Payne, S., 2016. Unpacking the impact of older adults' home death on family care-givers' experiences of home. *Health & place*, 38, pp.103-111.

Molyneaux, V., Butchard, S., Simpson, J. and Murray, C., 2011. Reconsidering the term 'carer': a critique of the universal adoption of the term 'carer'. *Ageing & Society*, 31(3), 422-437.

Moreno-Colom, S., 2017. The gendered division of housework time: Analysis of time use by type and daily frequency of household tasks. *Time & Society*, 26(1), pp.3-27.

National Audit Office., 2014. *Adult social care in England: overview*. ISBN: 9781904219095. Available: <https://www.nao.org.uk/wp-content/uploads/2015/03/Adult-social-care-in-England-overview.pdf> (Last accessed 9th February 2018)

Opdenakker, R., 2006. Advantages and disadvantages of four interview techniques in qualitative research. *Forum Qualitative Sozialforschung/Forum: Qualitative Social Research*. 7 (4).

Pain, R., 2006. Paranoid Parenting? Rematerializing Risk and Fear for Children. *Social and Cultural Geography*, 7:1, 221-243.

Power, A., 2013. Making space for belonging: Critical reflections on the implementation of personalised adult social care under the veil of meaningful inclusion. *Social science & medicine*, 88, 68-75.

Riessman, C. K., 2008. *Narrative methods for the human sciences*. Sage.

Rose, G., 1993. *Feminism and Geography: The Limits of Geographical Knowledge*. Polity Press, Cambridge.

Silman, J., 2016. Care Act 'failing to deliver' as carers face long waits for assessments, (online). *Community Care*. <http://www.communitycare.co.uk/2016/05/07/care-act-failing-deliver-carers-face-long-waits-assessments/> [Accessed 6 September 2017].

Rees, A., Holland, S. and Pithouse, A., 2012. Food in foster families: care, communication and conflict. *Children & Society*, 26(2), pp.100-111.

Twigg, J., Wolkowitz, C., Cohen, R.L. and Nettleton, S., 2011. Conceptualising body work in health and social care. *Sociology of Health & Illness*, 33(2), 171-188.

Valentine, G., 2001. *Social Geographies: Space and Society*. Pearson Education Ltd: Essex.

Watson, N., McKie, L., Hughes, B., Hopkins, D., & Gregory, S., 2004. (Inter) Dependence, Needs and Care: The Potential for Disability and Feminist Theorists to Develop an Emancipatory Model. *Sociology*, 38(2), 331-350.

Wengraf, T. and Chamberlayne, P., 2006. Interviewing for life-histories, lived situations and personal experience: The Biographic-Narrative Interpretive Method (BNIM) on its own and as part of a multi-method full spectrum psycho-societal methodology. *Short Guide to BNIM interviewing and interpretation*.

Williams, A.M., 2004. Shaping the practice of home care: Critical case studies of the significance of the meaning of home. *International journal of palliative nursing*, 10(7), pp.333-342.

Williamson, I., Leeming, D., Lyttle, S. and Johnson, S., 2012. 'It should be the most natural thing in the world': exploring first-time mothers' breastfeeding difficulties in the UK using audio-diaries and interviews. *Maternal & child nutrition*, 8(4), pp.434-447.

Yeandle, S., & Cass, B., 2014. Working carers of older people: steps towards securing adequate support in Australia and England? In Kröger, T., & Yeandle, S. (Eds). *Combining paid work and family care*. Policy Press, Bristol, pp.71-88.

Yeandle, S., Kröger, T., & Cass, B., 2012. Voice and choice for users and carers? Developments in patterns of care for older people in Australia, England and Finland. *Journal of European Social Policy*, 22(4), 432-445.

Zwet, J., Croix, A., Jonge, L. P., Stalmeijer, R. E., Scherpbier, A. J., & Teunissen, P. W., 2014. The power of questions: a discourse analysis about doctor–student interaction. *Medical education*, 48(8), 806-819.