



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

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ARTICLE INFO

Keywords:

Home
Care
Responsibility
Reciprocity
Identities
Family
Extraordinary normalcy

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 whilst caring, 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.

1. 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 'carer' on a par with 'care recipient'. Whilst policy attention is given to caring, 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 (Molyneux 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 'normalcy' 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, 2014; Molyneux 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; Molyneux 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. Molyneux et al. (2011) suggest that such terminology positions actors '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 observed by Lloyd

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(2006), means many individuals are resistant to or unaware of available support. Indeed, dis-identification with the term 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', Molyneux et al. (2011:422) argue, is a 'mark of bureaucracy, turning what is a normal human experience into an unnecessarily complex phenomenon'. Our data also suggests that the terminology formalises the experience of caring, removing it from everyday spaces and relationships. Following Molyneux et al. (2011), who suggest 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 normalcy of everyday life. Extraordinary normalcy locates care in the everyday, as advocated by Molyneux et al. (2011), and attends to the complexities of care often missing from social policy discourse (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 are manifest, and consider how concepts of responsibility, reciprocity and role reversal provide explanatory frameworks that normalise extraordinary aspects of care.

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.

1.1. 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, 2013). 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, 2013). UK government spending cuts have impacted dramatically on social care provision (Local Government Association (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) and carers are absorbing the impact of reductions in state funding and provision (Yeandle and Cass, 2013). 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; Kröger and Yeandle, 2013).

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 Care Act 2014, which states carers have a right to a needs assessment, potentially resulting in assistance 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 the support they are entitled to (Guest et al., 2015).

Home is a complex site; a memory, emotion, geographical location or physical building, loaded with meanings and emotion. Domestic activities – such as food provision – are laden with material, emotional and relational significance (Hamburg et al., 2014; Rees et al., 2012; 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 (Del Busso et al., 2018; 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 et al., 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 re-configure 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 spatialised interactions and highlighting the interaction between time and space in experiences of care across the life-course (Bowlby, 2012). We consider temporalities of care in more detail elsewhere (Guest et al., 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., 2012), 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.

2. 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 Healthwath Essex, 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

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