



Personal identity and the role of ‘carer’ among relatives and friends of people with multiple sclerosis[☆]



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ARTICLE INFO

Article history:

Available online 6 August 2013

Keywords:

UK
Carer
Caregiver
Identity
Informal care
Multiple sclerosis
Narrative
Qualitative research

ABSTRACT

Informal caregiving continues to be a crucial part of health and social care provision in the developed world, but the processes by which the identity of informal caregiver is conferred, or assumed, remain unclear. In this article we draw on data from a qualitative research study which examined the experiences of family members and friends of people with multiple sclerosis (pwMS) to explore how they interpret the label ‘carer’. We conducted narrative interviews with forty people throughout the United Kingdom between June 2011 and January 2012. Participants were spouses, partners, parents, children, siblings or friends of people who have had multiple sclerosis between 6 months and fifty years. We carried out thematic analysis of the interviews, informed by identity theory. Identity theory illuminated variation in peoples’ perceptions of themselves as carers, suggesting that self-identification with the role and label of carer is nuanced, shifting and variable. We propose a taxonomy of caring activity including emotional support, personal care, physical care, household tasks, advocacy and activism and describe four categories, with fluid and overlapping boundaries, in which the identity of carer was apparently embraced, enforced, absorbed or rejected. Variability and fluidity in self-identification as a carer are related to apparent expectations about whether one *should* assume a caring role. Those who were caring from the more tangential (and less taken for granted) relationship of sibling or ex-partner were among those who apparently embraced the role. Those who were expected to assume the caring role (typically spouses) were not always comfortable with doing so. It may be difficult to gain acknowledgement from family members and others that they occupy the role of carer if people resist the label as a bureaucratisation of their personal relationships.

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Introduction

The words ‘carer’ or ‘caregiver’ are commonly used to describe a person who gives significant amounts of help over long periods of time to a relative, friend or neighbour who is ill or disabled. This ascribed role is deemed important economically, saving billions of pounds that would otherwise have to be spent on health and social

care services. As a measure of this importance, there has been a campaign in the UK to give the word ‘carer’ protected status (Lloyd, 2006), whereby its use would be confined to describing the activity of so-called ‘informal care’ as opposed to health and social services supplied by paid workers.

The challenges, and potential rewards, of informal caregiving in the developed world have been documented in international literature over many years (Archbold, Stewart, Greenlick, & Harvath, 1990; Nolan, 2001; Robinson, 1983; Schumacher, Stewart, & Archbold, 2007). Studies in Canada, the United States and Australia suggest that the role of informal caregiver is disproportionately occupied by women and is seen to have negative effects on their health (Calasanti & King, 2007; Guberman, Maheu, & Maillé, 1992; Lee & Gramotnev, 2007; Lee & Porteous, 2002). In spousal caregiving relationships, the impact of ‘caregiver burden’ is affected, across Western societies, by the quality of the relationship within the couple (Badr, Acitelli, & Carmack Taylor, 2007; Boeije, Duijnste, & Grypdonck, 2003; Boeije & van Doorne-Huiskes, 2003; Coeling,

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Biordi, & Theis, 2003; Schumacher et al., 2007; Starks, Morris, Yorkston, Gray, & Johnson, 2010) and by the extent of family and other support networks (Bowen, MacLehose, & Beaumont, 2011; Neufeld & Harrison, 2003).

In most European countries it is still assumed that unpaid work by informal carers will supplement formal care provision (Triantafyllou et al., 2010, p. 43). In the United Kingdom, for more than two decades campaigners, policy makers and researchers have attempted to make visible a supposed hidden population of carers, usually reported to be around 6 million people, to identify their needs (Arksey & Glendinning, 2008; Sothill et al., 2001), understand their experiences across a wide range of conditions (Krajo, Brouwer, de Leeuw, Schrijvers, & van Exel, 2011; McLaughlin et al., 2010; O'Brien, Whitehead, Jack, & Mitchell, 2012; Olson, 2011) and implement policies that will enhance their support. There is particular concern to identify and support young carers (Smyth et al., 2011).

Since the publication of the National Carers Strategy in England (DOH, 1999, 2010) there have been renewed efforts to identify and support carers (Jones, Mackenzie, Greenwood, Atkins, & Habibi, 2012). This is an ongoing process which some feel needs the force of legislation, though a Private Member's Bill in the UK House of Commons, designed to enhance the identification and support of carers, failed to make parliamentary progress (Carers Identification and Support Bill, 2010–12, www.parliament.uk).

A widespread finding in research with informal carers is that many people do not identify with the term 'carer' because they perceive their helping activities as a normal part of the relationship that they have with a person who is ill or disabled (Bowen et al., 2011; Henderson, 2001; Molyneaux, Butchard, Simpson, & Murray, 2011; O'Connor, 2007; Smyth et al., 2011). Molyneaux et al. (2011) go so far as to suggest abandoning use of the term 'carer' altogether. They examine literature in various 'caring contexts' — mental health, palliative care, older adulthood and dementia, physical and intellectual impairments — and argue that there has been 'consistent failure of the term 'carer' as a recognisable and valid description of the relationship between 'carers' and those for whom they care' (p. 422). They also argue that use of the term may imply burden (indeed the phrase 'carer burden' is common in the literature) leading to a devaluation of the individual who is cared for. In such circumstances the reciprocity and mutuality which is seen to characterise many relationships between caregiver and cared for (Nolan, 2001) may remain under-acknowledged. Molyneaux et al. (2011) conclude that 'descriptions of the caring relationship that focus on the relationship from which it arose would be both more acceptable and useful to those it concerns' (p. 422).

Multiple sclerosis

Multiple sclerosis (MS) is an inflammatory disorder of the central nervous system (CNS). It is characterised by lesions and scarring of the protective myelin sheath of CNS neurons, leading to neuronal damage and axonal loss (Burgess, 2002; Keegan et al., 2002). The course of the disease is uncertain but as it progresses the person with MS may face physical problems including muscle weakness, impaired use of limbs, spasticity, bladder and bowel dysfunction, sexual dysfunction, problems with speech and swallowing and visual difficulties (Schapiro, 2007). There may also be hidden difficulties such as fatigue, dizziness and pain and, as the disease advances, cognition problems such as short-term memory loss, lack of personal insight or forward planning and mood swings (Burgess, 2002).

Approximately 85% of people with multiple sclerosis present with the relapsing-remitting form, characterised by episodic

relapses and remissions that may be partial or complete (Murray, 2006). Usually after around 10 years, about half of people with relapsing-remitting MS will go on to develop secondary progressive MS, where symptoms gradually worsen and there are fewer or no periods of remission. Progression from onset affects around 15% of people diagnosed and is defined as primary progressive MS. In this type, symptoms gradually get worse from the outset and there are few or no periods of remission. Fifteen per cent of people with relapsing-remitting MS have a mild course with minimal disability after 15 years, called 'benign' multiple sclerosis (Murray, 2006).

Caring and identity

In this article, drawing on a study of 40 relatives or friends of people with MS, we explore ways in which people presented and talked about their identities in relation to a person with multiple sclerosis (pwMS) and the extent to which they identified with the term 'carer'. We interpret our findings from the perspectives of identity theory, particularly as explicated by Stryker and colleagues (Stets & Burke, 2000; Stryker & Burke, 2000).

Social scientists have theorised about identity in at least two parallel strands, rooted in and expanding the seminal theoretical work of Erikson (Schwartz, 2001) and elaborating on GH Mead's ideas about the relationship between self and society (Stryker & Burke, 2000). Identity theory focuses on the roles people occupy (what one does) as the basis for identity, while social identity theory emphasises social structure, or group belonging (who one is) as a source of identity (Brown, 2000; Stets & Burke, 2000; Stryker & Burke, 2000). These two theoretical approaches are increasingly convergent in some views (Stets & Burke, 2000) and it is widely acknowledged that people have multiple identities, grounded in the occupancy of multiple roles and diverse group memberships. Multiple identities may reinforce or conflict with each other (Stryker & Burke, 2000).

Role-based identities appeared to be more common than group-based identities among participants in the study reported here, though it should be noted that there is overlap between roles and categories and that people frequently (inevitably) occupy roles at the same time as participating in membership of social categories (Stets & Burke, 2000). In the present context, for example, 'carer', 'husband/wife/partner/spouse', 'son', 'sister', 'best friend', are all at the same time instances of roles and categories.

Methods

Sample and recruitment

We conducted 40 narrative interviews with people who self-identified as a relative or friend of someone with multiple sclerosis. A diverse sample of participants was recruited through newspaper adverts, carers' groups, posts on MS charity websites, and (in a few cases) by snowballing through existing contacts. Following initial contact with the research team to express interest in taking part, potential recruits were mailed a detailed Participant Information Sheet and a personal details form, which they returned to the research office in a pre-paid envelope. They were then contacted by phone in order to answer any queries about the study, to confirm agreement to participate and to arrange the interview. Written consent was gained at the time of interview. The study was approved for multi-site recruitment by the Berkshire Research Ethics Committee.

We sought a maximum variation sample (Coyne, 1997) in order to capture a wide range of different experiences. Thus, we interviewed 19 men and 29 women, aged 17–75, who were spouses/partners (27), siblings (2), children (5), parents (4) and friends (2) of

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