



Improving the interface between informal carers and formal health and social services: A qualitative study



K.M. McPherson^{1,*}, N.K. Kayes¹, N. Moloczij¹, C. Cummins¹

Person Centred Research Centre, Health and Rehabilitation Research Institute, AUT University, Private Bag 92006, Auckland 1142, New Zealand

ARTICLE INFO

Article history:

Received 17 December 2012
Received in revised form 13 July 2013
Accepted 14 July 2013

Keywords:

Carers
Quality of health care
Qualitative research
Disability
Delivery of health care

ABSTRACT

Background: Reports about the impact of caring vary widely, but a consistent finding is that the role is influenced (for better or worse) by how formal services respond to, and work with informal carers and of course the cared for person.

Objective: We aimed to explore the connection between informal and formal cares and identify how a positive connection or interface might be developed and maintained.

Design: We undertook a qualitative descriptive study with focus groups and individual interviews with informal carers, formal care service providers and representatives from carer advocacy groups. Content analysis was used to identify key factors impacting on the interface between informal and formal carers and propose specific recommendations for service development.

Setting: Community setting including urban and rural areas of New Zealand.

Participants and methods: Seventy participants (the majority informal carers) took part in 13 focus groups and 22 individual interviews.

Results: Four key themes were derived: Quality of care for the care recipient; Knowledge exchange (valuing carer perspectives); One size does not fit all (creating flexible services); and A constant struggle (reducing the burden services add). An optimum interface to address these key areas was proposed.

Conclusion: In addition to ensuring quality care for the care recipient, specific structures and processes to support a more positive interface appear warranted if informal carers and services are to work well together. An approach recognising the caring context and carer expertise may decrease the additional burden services contribute, and reduce conflicting information and resultant confusion and/or frustration many carers experience.

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What is already known about the topic?

- The number of people acting as informal carers is growing.

- The contribution informal carers make is crucial for sustainable health services.
- Current evidence indicates carers find working with health and social services problematic.

What this paper adds

- Health and social services appear to make the circumstances of informal caring even more difficult such that it feels a 'constant struggle'.
- Key factors that services could incorporate to be more responsive include greater consideration of two way

* Corresponding author at: Person Centred Research Centre, Akoranga Drive Campus, AA Building, Room 263, Private Bag 92006, Auckland, New Zealand. Tel.: +64 9 921 9999x7110; fax: +64 9 921 9620.

E-mail address: Kathryn.McPherson@aut.ac.nz (K.M. McPherson).

¹ On behalf of the AUT Caring Interface Research Group.

knowledge exchange, and a focus on ‘human caring’ within quality of care frameworks.

- Findings have been synthesised into a proposed optimum interface between formal services and informal carers that could be incorporated into practice.

1. Introduction

Informal carers play a key role in supporting sick and disabled people in their health, wellbeing and participation. It is thought at least 12% of the population in England (around 5 million people) are carers (The NHS Information Centre, 2010), with a similar percentage (100 million people) in Europe (Eurocarers: European Association for Working Carers, 2008). In the USA, 29% (65 million) are providing care for a chronically ill, disabled or aged family member or friend (National Family Caregivers Association, 2011). The number of informal carers is expected to grow significantly due to de-institutionalisation, our ageing population, and changing family structures (Pickard, 2004). The economic ‘value’ of this care is estimated as US\$375 billion a year in the USA (National Family Caregivers Association, 2011), and £119 billion in the UK in 2011 (Carers UK, 2011), the latter being more than the entire annual expenditure of the National Health Service (NHS). The significance of this contribution is recognised in health and social policy in many countries, including where this study was based in New Zealand (Ministry of Social Development, 2007a, 2008). Sustainable health services depend on supporting informal carers’ health and well-being (Carers UK, 2011; Low et al., 1999; Ministry of Social Development, 2007b).

Extensive research exists concerning carer burden and/or stress with many studies finding a moderate relationship between the severity of the care recipient’s needs and level of distress/risk of ill health for the caregiver (Schulz and Sherwood, 2008). However, other studies report positive benefits of caring (Hunt, 2003), even enhancing longevity for the carer (Brown et al., 2009). This mix of findings supports an argument that a complex array of factors variably influence the impact of caring on any one carer over time, including the nature and severity of the impairment/disability, the carer’s own health, well-being and personality, the interpersonal nature of the relationship, and a range of contextual factors including family demands and financial pressure (Im et al., 2004; Kim and Schulz, 2008; Morse et al., 2012; Ory et al., 1999; Schulz and Beach, 1999; Schulz and Martire, 2004; Schulz and Quittner, 1998; Schulz et al., 1990, 1995, 1997; Smith et al., 2011; Vitaliano et al., 1997).

Whilst research improving prediction of negative health or social consequences for individual carers has clear merit, our own and others’ research suggests ‘universal precautions’ may be warranted regarding the points of interaction (or interface) between formal services and informal carers. This appears a ubiquitous factor contributing to, or alleviating, difficulties carers experience. For example, a great deal of research highlights difficulties in communication (Carers UK, 2011) and prior difficulty in ensuring continuity and reliability of service delivery may lead people avoid interaction with formal

services (Fadyl et al., 2011). Whilst many carers ‘make do’ without external support in providing care and support (The NHS Information Centre, 2010), at some point they will necessarily interact with health and social services with, or on behalf of, the person they support with benefit assessments and/or medical attention or hospitalisation being needed for the care recipient, or the carer. Given this interface is amenable to change, clarity on what comprises an optimum interface offers real potential for more responsive and improved services.

Recent reviews highlight services (particularly in cancer and dementia care) are aiming to better support carers (Hudson et al., 2010; Parker et al., 2010), and moves to include carers in the design of services for these populations are in progress (The British Psychological Society, 2010). However, reports of difficulties continue (Kim and Schulz, 2008; Mansell and Wilson, 2009, 2010; Monin and Schulz, 2009; Smith et al., 2011). Of particular interest, little research specifically focuses on what is needed to ensure a better meeting point (or interface) and our study aimed to address this gap by:

- a) exploring carer and professional perspectives on how informal care givers and formal services interface with one another
- b) identifying how formal services could better interface with informal carers.

2. Methods

A qualitative descriptive design (Sandelowski, 2000) was used to identify what participants thought were key components of services that *worked well*. Whilst all qualitative designs have a level of interpretation, qualitative description differs from other approaches (for example phenomenological or grounded theory description) in that the level of interpretation is low-inference. This approach is targeted at identifying ‘the facts’ about a topic, and the meaning participants ascribe to those facts and is considered particularly appropriate when a key goal of the research is to inform practice (Sandelowski, 2000). We considered the most appropriate interpretation would come from a social constructionist perspective (Crotty, 1998) because ‘an interface’ is by definition constructed by multiple players and this influenced our sampling (including both informal and formal carers), as well as our data collection and analysis.

Participants were eligible to take part if they were: involved in caring for a sick or disabled person in a formal (paid), or informal way, or were carer advocates; available to participate in an individual or group interview; and able to communicate in English. We used purposeful sampling (Strauss and Corbin, 1998) to facilitate maximum variation in the sample aiming for diversity of informal carers in: nature of illness/disability of the person supported (e.g. physical, cognitive, intellectual, mental health, palliative care); care giving role (e.g. primary/secondary caregiver; co/non resident); relationship (e.g. parent, spouse, child, friend); ethnicity; and age of carer. Demographic detail for informal carers is provided in Table 2. Carer advocates were purposefully selected aiming for breadth of

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