



Understanding the conceptualisation of risk in the context of community dementia care



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ABSTRACT

Risk has become a ubiquitous presence in modern society. For individuals diagnosed with dementia this pre-occupation with risk can affect their day-to-day life in many ways. Maintaining autonomy while balancing risks is a continual struggle not only for those living with the disease, but also their carers, family and health professionals. To understand how these different groups of individuals conceptualise the issue of risk for those living with dementia, 83 semi-structured interviews were conducted with people living with dementia, carers, older people without significant experience of dementia, and registered nurses, and staff from a community nursing organisation. These interviews were analysed using Thematic Analysis, which suggested that the risks identified by each group were grounded in their experiences and perspective on dementia. Furthermore, context and understanding of the individual living with dementia and their preferences was central to effectively managing risk in a balanced way, ensuring that 'acceptable risks' were taken to ensure an acceptable quality of life for all involved. These findings highlight that there is no single approach to risk which can be applied to all individuals; rather, a negotiation needs to take place that takes into account the individual's preferences alongside their available resources and means.

1. Introduction

Risk has become a ubiquitous and pervasive presence within contemporary life. An element of the maturation into adulthood in modern society involves learning to recognise, respond to and manage risk within a society that has become "increasingly preoccupied with the future (and also with safety), which generates the notion of risk" (Giddens, 1998, 27). What happens, however, when one's capability to recognise, respond to or manage risk is brought under doubt, or labelled as impaired? This is the experience individuals with dementia undergo continually from the point at which their capacity is questioned, through to diagnosis and management.

Dementia is a growing concern worldwide. Approximately 46 million people globally experience a diagnosis of dementia, with this number expected to increase to 131.5 million by 2050 (Prince et al., 2015). While many individuals may equate dementia to a loss of memory, the reality, however, is that dementia is a syndrome that can affect not one but many cognitive domains. These domains include memory, but also incorporate behaviour, thinking, judgement, language, and personality (Australian Institute of Health and Welfare,

2017; World Health Organisation, 2016). There are many different types of dementia, with Alzheimer's Disease being the most common (accounting for approximately two-thirds of diagnoses; World Health Organisation, 2016). The course of the disease varies greatly both within and across the different types of dementia, and there is currently no cure (Australian Institute of Health and Welfare, 2017).

In many instances, being bestowed with the label of 'dementia' diminishes the individual in the eyes of others. A diagnosis of dementia is often seen to be akin to losing capacity, irrespective of the stage or progression of the disease. This immediately designates the individuals as 'at risk' and unable to engage in or manage aspects of their life that, up until that moment in time, they were deemed as capable of managing for themselves. While the identification of risk is intended to prevent danger or harm coming to the person with dementia or those around them, this all-consuming approach assumes that something can (and should) always be done to prevent negative outcomes, even at the expense of the person diagnosed with dementia, for whom the risk is most salient (Adams, 2001; Clarke, 2000; Lupton, 2013).

Risk – by necessity – shifts the focus from the present to the future, as it focusses on what *may* happen, rather than what is happening *right*

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now (Beck, 2000; Green, 2007; Rigakos and Law, 2009). Risk is ultimately defined by cultural perceptions and meanings, which shift and change over time (Adams, 2001; Beck, 2000; Bond et al., 2002; Lupton, 2013; McDermott, 2010). Even within cultures, risk holds different meaning to different individuals, and can change in different contexts and across time (Stevenson et al., 2017 #188)(Green, 2007; Lupton, 2013; Manthorpe and Moriarty, 2010; Mitchell and Glendinning, 2007). Furthermore, individuals with dementia, carers and health professionals are heterogeneous groups. As such, all individuals situate concepts such as risk in the context of their cultural, personal, and professional experiences. Therefore, no two individuals are likely to have the same perspective on a single risk, despite belonging to the same ‘category’ (Berry et al., 2015; Douglass, 1992).

In addition to the varying perspectives and definitions on risk, the discourse around risk often fails to reflect the benefits that may stem from taking risks, instead focussing on the negative ramifications should the identified risk be realised (Adams, 2001; Alaszewski and Manthorpe, 2000). Each individual’s ‘risk appetite’ is different, and in modern life there are often circumstances in which individuals choose to stay at risk (Buri and Dawson, 2000; Manthorpe and Moriarty, 2010). Understanding this complexity in the identification and management of risk is particularly important when considering situations when an individual’s capacity to make an informed choice is uncertain, such as when an individual is diagnosed with dementia (Buri and Dawson, 2000; Manthorpe and Moriarty, 2010).

Within health-related service provision, risk is seen as “an objective reality that can be measured, controlled and managed ... using mathematical models to measure and predict risk” (Lupton, 2013, 20). The knowledge and experience of health professionals regarding diseases such as dementia are often seen as more valuable within the health care setting than those directly experiencing the disease, and as such, a distinction is often made between the scientifically measured and systematically identified ‘real’ risks detected by ‘experts’, and the ‘unscientific’ identification of risk by ‘lay’ individuals (Adams, 2001). However, in understanding and managing the day-to-day experience of people with dementia and the risk that they face, considering the perspective of people with dementia and their carers are important as they possess a different kind of knowledge – knowledge of the individual, including their lived experience and the wider context in which decisions are being made (Beattie et al., 2004; Clarke, 2000; Wynne, 1996 as cited in Lupton, 2013; Taylor-Gooby, 2006).

Given the pressures of the modern health care system, it is not uncommon for health professionals to base decisions relating to risks on the presenting diagnosis, rather than the capacity and abilities of the individual (Carr, 2010). This approach emphasises the processes involved in the identification and management of risk (e.g. assessments, procedures), disregards the positive benefits that may be derived from taking a risk, and reduces the capacity of professionals to be sensitive to the needs and preferences of individuals (Adams, 2001; Alaszewski and Manthorpe, 2000; Green, 2007; Rothstein et al., 2006). This is particularly concerning in dementia as the trajectories of disease can be wildly divergent – even within similar diagnoses (Manthorpe and Moriarty, 2010; Mendez et al., 2008). Furthermore, this tendency to assume loss of capacity results in miscalculations of the risk that individuals are facing, not only to overestimate, but also underestimate the risk that the individual and their carers and family face (Bond et al., 2002). As a result of the emphasis on diagnoses and processes, there has been a radical reduction in the use of proactive problem-solving and risk-taking in these professions (Green, 2007), which may prevent patients from achieving improved health and wellbeing – despite disease and/or disability. In maintaining meaning and quality of life for individuals living with dementia, the challenge remains to find a balance between the identified risks and quality of life, while acknowledging that risk cannot be eliminated completely (Manthorpe and Moriarty, 2010; McKeown et al., 1999).

In speaking about social workers in the community, Green (2007)

indicates that these workers are confronted daily with the reality of making decisions about risk not only with but sometimes on the behalf of people living with dementia, which then must be acted upon once identified. Furthermore, he states that social workers are “now having to resolve competing professional, administrative, ethical, and political interpretations of their client’s freedom and choice while managing objective dangers and identified risks in complex community settings” (p. 398). This is also true for other health professionals, such as community nurses, who provide general nursing care to individuals in their place of residence. It has been found that health professionals tend to focus on the physical domain (e.g. falls, nutrition, medication), and management strategies that focus on the future (Clarke, 2000; Gilmour et al., 2003; Robinson et al., 2007), while carers tend to focus on the interpersonal domain (e.g. loss of relationships) and management strategies that focus on the present (Robinson et al., 2007; Stevenson and Taylor, 2016). It has been identified that people with dementia experience risk through the lens of emotion, and that day-to-day issues are most in focus, such as daily activities and socialising, alongside mental health issues and the biographical loss that the progression of dementia brings, such as loss of self-identity (Robinson et al., 2007) (Stevenson et al., 2017 #188).

Currently in Australia over three-quarters of people diagnosed with dementia are living in the community. Given the projected increases in dementia prevalence in Australia this could result in over 840,000 Australians with dementia residing in the community by 2056 (Brown et al., 2017). In order to provide effective and acceptable services to people living with dementia and their families, a clear understanding of the risks relating to dementia and related health care is required. This cannot be simply from a medical standpoint, however, as understanding the nuanced perspectives of people living with dementia and those around them will improve both individual and institutional responses to risk, and may assist in keeping people in their own homes for longer. This may not only improve outcomes for the individual living with dementia but may provide cognitive stimulation which has been shown to slow the progression of the disease and increase quality of life (Woods et al., 2012), all while keeping the individual in their own home. As such this paper aims to understand not only how risks are conceptualised, but the approaches and views relating to identification, and management of risk within a range of individuals.

Please note that for the purposes of this paper, ‘dementia’ will be used as an umbrella term to describe those diagnosed with the varying forms of dementia, including Alzheimer’s disease.

2. Method

This study is reported in accordance with the Consolidated Criteria for Reporting Qualitative Research (COREQ; Tong et al., 2007), and adheres to the dementia language guidelines published by Dementia Australia (n.d.).

2.1. Recruitment

Five distinct groups were recruited as part of this study; people living with dementia, carers of people living with dementia, older people without significant experience with dementia (labelled here as ‘older participants’), registered nurses working in the community nursing context (RNs), and staff from a community nursing organisation, comprising of senior nurses, social workers and management. While specific techniques for recruitment differed by group (described below), all participants were purposively sampled.

All participants were told that the researchers were from a community nursing organisation, were conducting research to understand risk in the context of dementia care and were creating a tool to facilitate discussions around what constitutes risk to an individual. No personal goals of the research team were divulged to participants. In addition, participants were assured that should they not wish to take part that it

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