



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

would not impact on any relationship with the community nursing organisation (if applicable). Informed consent was obtained from all individuals as described below. For people living with dementia the interviewers informally evaluated whether participants understood what was being asked of them and were able to provide consent – this evaluation was continuously reviewed by the interviewer throughout the interview to ensure informed consent was maintained.

2.2. People living with dementia and carers

Potential participants were contacted or contacted the research team by email; a small group telephoned and discussed participation over the phone. These individuals were asked to take part in snowball recruiting, whereby participants were asked to share details and recruitment materials (e.g. emails, or flyers) relating to the study with others where appropriate so that any interested parties could contact the research team. One carer organisation offered to hold a focus group with their members. After participants had agreed to participate they were provided with the Plain Language Statement (PLS) and consent form via email or mail (this was done in person for the single focus group). Some people living with dementia and carers were known to the research team before the study; the majority of which were professional relationships that did not impact on the data collection. Where a personal relationship was present between a research team member and participant, another member of the research team conducted the interview.

2.3. Older people without significant dementia experience

Older participants were recruited through metropolitan clubs affiliated with Bowls Australia. An individual from the community nursing organisation with a relationship with Bowls Australia facilitated an introduction for the research team with two club organisers, who provided recruitment materials and gauged interest in taking part in the research. Individuals were considered to not have significant dementia experience if they had not cared for someone with dementia or have an immediate family member with the disease. At both clubs individuals indicated interest, and a time was set up for the focus group to take place. There was no prior contact or relationships with older participants. Participants were provided the PLS and consent form at the time of the focus group.

2.4. Registered nurses (RNs)

RNs were recruited through the community nursing organisation at which the research was taking place. Managers in the community nursing organisation were asked to provide information to nurses in their geographical area and pass the details of interested individuals to the research team. The research team then contacted the nurses via email to further explain the study, after which a time for interview was set up and PLS and consent form provided via email.

2.5. Staff

Staff included senior nurses (generally those in specialist (e.g. dementia) or in management roles), social workers and management from the community nursing organisation at which the research was taking place. Individuals were identified by the research team, with roles targeted that had experience in the area of dementia and/or risk. Individuals were invited by the research team via email with initial information. Should an individual indicate interest in taking part, a time for interview was set up and PLS and consent form provided via email. Given that participants in this group worked in the same organisation as researchers, a professional relationship had been established with many participants at the time of interview. In order to ensure confidentiality for this group these individuals will be collectively

known as staff for the purposes of reporting.

2.6. Data collection

Interviews and focus groups were primarily conducted by MD (BA (Hons), PhD), a female Research Fellow with significant experience conducting research with vulnerable populations. DG (BA, PostGradDipSoc, MA, PhD), a female Senior Research Fellow with significant experience conducting research with vulnerable populations, and FOK (BN, MNsc, Nurse Practitioner), a female senior specialist nurse in dementia with significant experience with people living with dementia and some research experience, conducted the remainder of the interviews.

Interviews with people living with dementia and carers generally took place over the phone or in the individual's home; some elected to have the interview take place in a public place (e.g. café). The focus group for the carers took place at the carer organisation where their meetings were generally held. The focus groups for older participants took place at their bowls club, in a meeting room or similar. RN interviews either took place in a regional office of the community nursing organisation or in a café in the nurse's area of work. Staff interviews took place in a regional office of the community nursing organisation. All interviews were audio recorded using a digital voice recorder and transcribed verbatim by a professional transcription company. Transcripts were not returned to participants. Unless the interview took place in a public place (e.g. café) there was no one present beside the participant and researcher, to the best knowledge of the researcher. Data collection took place between October 2015 and August 2016.

A semi-structured interview schedule was developed and piloted with initial participants. Data collection continued until data saturation was reached, or all avenues for recruitment exhausted.

2.7. Data analysis

Thematic analysis was used as the analysis technique for this study. Thematic analysis is a “method for identifying, analysing and reporting patterns (themes) within data” to find “repeated patterns of meaning” (Braun and Clarke, 2006, 79–86). The six phases of thematic analysis described by Braun and Clarke (2006) of familiarisation, generation of initial codes, searching, review and naming of themes, followed by report production were used. An inductive strategy was adopted, and the phases of analysis treated in a reciprocal manner, allowing movement back and forth between the phases as required. MD was primarily responsible for data analysis, however regular discussions were held within the research team and the project reference group to provide further insight to the themes arising from the analysis. Participants were not provided an opportunity to provide feedback on the findings. NVivo 11 (Q. S. R. International, 2016) was used as a tool to assist qualitative analysis.

2.8. Sample description

Ninety-two individuals were invited to participate; 80 (87.0%) agreed to do so. Those who did not participate either ceased responding to attempts by the research team to contact them ($n = 8$, 8.7%), or declined participation ($n = 4$, 4.3%). The majority of participants lived in Victoria. The age of participant greatly differed by participant type (See Table 1), however overall participants were aged between 26 and 89 years ($M = 59.8$, $SD = 15.5$). Interview and focus group duration ranged from 11 to 76 min (mean 33 min).

For carers, older participants and people living with dementia, the Index of Relative Socio-Economic Advantage and Disadvantage (IRSAD) was used as a proxy for socioeconomic status. The IRSAD ranks postal areas on a continuum from the most disadvantaged to the most advantaged (Australian Bureau of Statistics, 2013). The mean scores of 8.0 and above indicate that overall, these groups reside in areas considered

Table 1
Demographic characteristics of participants.

	Carer	Healthy Older People	Person Living with Dementia	Registered Nurse	Staff
n	22	20	7	8	23
Gender, female, n, %	16, 76.2%	11, 55.0%	3, 42.8%	8, 100.0%	22, 95.7%
Age; M, (SD)	69.2 (8.7)	73.3 (5.0)	66.0 (11.6)	34 (9.6)	49.0 (7.3)
IRSAD; M, (SD)	8.0 (2.4)	8.95 (1.5)	7.1 (3.7)	–	–
Years since diagnosis, M, (SD)	5.4 (4.0)	–	4.5 (2.2)	–	–
Years in Current Role; M, (SD)	–	–	–	4.6 (3.7)	7.1 (9.1)
Years of Experience with Dementia; M, (SD)	–	–	–	10 (7.6)	20, (9.7)

IRSAD = Index of Relative Socio-Economic Advantage and Disadvantage.

to have high levels of socioeconomic advantage. For carers and people living with dementia the mean time since diagnosis was approximately five years. RNs had been in their current role on average four and a half years, and had a decade of professional experience with dementia. Staff had been in their current role on average seven years, with around two decades' professional dementia experience.

Given the varying cultural and social meanings associated not only with dementia but also with risk, this paper uses the tenets of hermeneutic risk discourse as a framework to assist in the understanding and interpretation of findings. This account of risk emphasises the 'lived experience' of individuals and how reality is interpreted within a certain sociocultural setting (Lupton, 2013).

3. Results

The main themes that emerged during the inductive exploration were the identification, management and ramifications of risk in dementia care, as well as the competing conceptions of the meaning and implications of dementia. Finally, the concept of acceptable risk and enablement emerged as a final theme within the data.

3.1. Identified risks

In identifying the risks present for individuals living with dementia, participants drew on their own experience and construction of risk, weaving activities and tasks they identified as 'risky' into their narratives. While it was common to discuss a range of different risks (59 different risks were identified by participants), there were few risks that were identified by each of the participant groups within this study. Only cooking, medication, falls, driving, responsive behaviours (such as aggression, restlessness and disinhibition), social isolation and dressing were identified by all four participant groups.

Fig. 1 depicts the percentage of participants in each of the four groups who identified each of the most common ten risks. As can be seen in the figure, Staff and RNs often had the highest proportion of individuals identifying a risk, with the exceptions of driving, responsive behaviours, carer stress and social isolation. People living with dementia identified issues that significantly impact on them on a continuous basis, such as social isolation and driving. No people living with dementia identified the issue of carer stress as a risk (alongside food and nutrition, hygiene, and 'wandering').

The risks most salient to the people living with dementia emphasised the experience of loss of independence, such as driving, working and finances. In particular, the experience of isolation and responsive behaviours were also highly salient to this group. In addition, people living with dementia spoke of activities for which they continued to engage with support, such as housework, hobbies, cooking, and exercise;

Oh yeah, [walking the dog by myself is] a must do every day. I walk her for about 20 minutes and we don't mess around. It's a fair sort of a crack that we go at ... [my wife is] not a walking type person, especially up and down hills and that's the exact sort of area that we live in. She wouldn't enjoy it at all. (Person living with dementia_006)

Carers expressed desire to ensure that those they cared for were not only happy but safe, and this desire ensured that the risks identified by this group were as many and varied as the people that they cared for. The risks most salient to this group, however, were those that had significant ramifications not only for the person living with dementia, but those around them. These included driving, cooking, responsive behaviours, and having negative reactions to full time or respite care. In particular, the stress that is placed on carers looking after a person living with dementia was a significant concern. Sometimes, however it was the simple everyday activities that carers spoke about;

You think washing dishes or making a cup of tea would be simple, but I've given up now because I've put the dishes in the water, make sure everything's ideal, the dish rack is there and everything else, and what does she do if she does it, is she'll take them out, doesn't rinse them. She just pulls them out of the water and puts them in the dish rack. So I then have to come and wash them. You see? So that's no help (Carer_006)

For older participants, their overall lack of social contact with people living with dementia ensured that social stereotypes were often drawn upon when discussing risk. This ensured that discussion focussed on those risks that were most likely to cause high levels of harm should they be realised. These include activities such as cooking that could result in physical harm; financial abuse; and the considerable stress that is placed on those who care for people living with dementia.

Sometimes it's worse for the carer ... they kind of lose their spouse or friend. They're no longer the person they knew. (Older Participant FG3)

For nurses and staff, years of training and experience in caring for individuals within the health sector meant that the focus was generally on the health-related risks – particularly those relating to the care provided by the community nursing organisation. Medication, food and nutrition, cooking, falls and hygiene were some of the most common risks discussed by this group. In addition, those individuals with comorbidities such as dementia and diabetes were seen to be a particularly vulnerable group as they were susceptible to risks relating not only to nutrition but medication, leading to severe adverse consequences, even death;

The people who have diabetes and dementia are probably our highest risk areas because they could just hypo or hyper and be dead ... they are really hard to manage (Staff_016)

Overall, participants' narratives illustrated the complexity and contextual nature that underlies the concept of risk, particularly in dementia care. As a number of participants acknowledged, what is identified as a risk differs from individual to individual, even before a diagnosis of dementia is part of the equation;

Normally all risks aren't the same for everyone are they? People'll go and do a bungee jump and the others think that's risky. (Older Participant FG02)

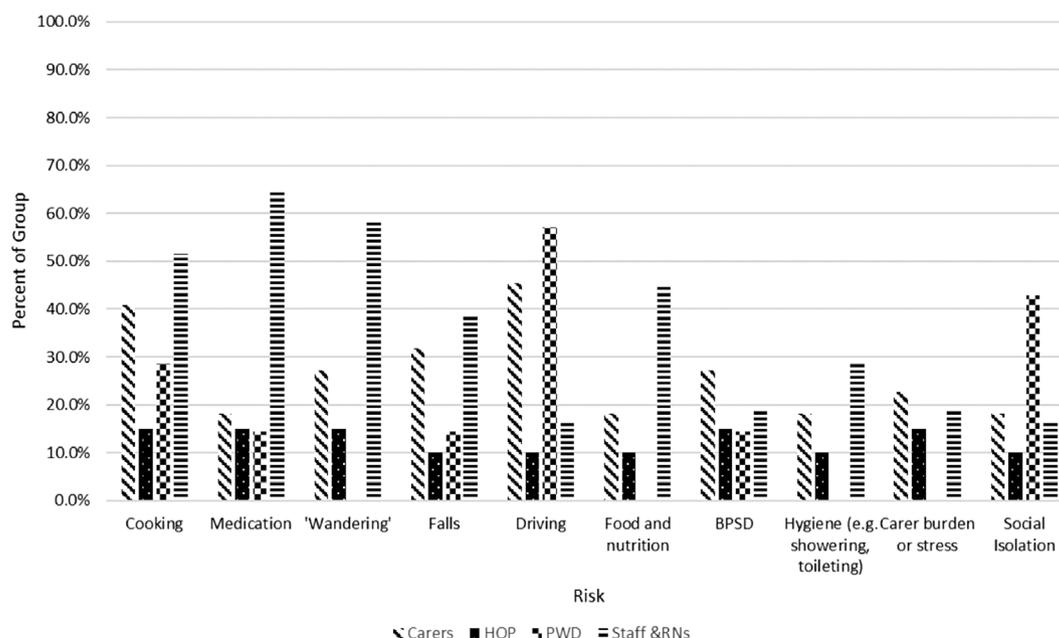


Fig. 1. Proportions of participants identifying the most common 10 risks.

3.2. Risk management

The approaches to managing risk were as varied as the risks presented by participants. Context and circumstance were seen as central to truly understanding the risks salient to the person living with dementia. When the person with dementia's history, preferences and circumstances before diagnosis were taken into account, some 'risky' behaviours – such as living alone – were seen in a new light, providing alternative avenues and strategies for managing those situations and their progression;

Mum was living alone which wasn't ideal. But before she had dementia she'd lived alone for 10 plus years since my father died. I think if Mum had dementia and she was living with my Dad, then my Dad died and half way through the dementia she was suddenly living alone, I think that's a very different situation to someone who's lived alone for 10 plus years and then develops dementia (Carer_003)

When approaching risk with people living with dementia, a prominent narrative – particularly from carers – was the importance of handling the identified risk sensitively. This was particularly true for those caring for people living with dementia who maintained some level of insight into their behaviour. Framing the way in which an individual was to give up the behaviour could make the experience more pleasant not only for the person with dementia, but those around them, making the transition smoother and simpler for all involved;

[The doctor] asked if he was driving. He said no, I've decided not to because it's a bit risky. So I've made the choice not to. The doctor gave him such a good rap and said you're such a responsible man and I'm pleased you've done this. Very responsible and I admire you. Once he did that, [he] felt really good about it, that he had done the right thing. So it was handled very well. (Carer_008)

For people with dementia, some attempted to maintain their independence and autonomy by continuing the tasks and activities that they had always done, however they modified them to ensure the safety of themselves and those around them;

I've actually got to replace a TV antenna, which is not overly difficult in itself, but now I'm going to wait until my partner is at home before I get up on the roof, because I find my sense of balance is not what it used to be. (Person Living with Dementia_003)

Some carers noted that certain activities were risky, but that they were too important for the person with dementia to not continue doing. This became a constant struggle and monitoring process that carers underwent to manage the benefit of the activity against the risk;

So the gardening, he was really quite unsafe, but I just couldn't bear to take it off him, but now he comes and brings the wheelie-walker out and sits on it and points. (Carer_010)

Incremental strategies were used to assist in the management of risks while maintaining independence where possible. Sometimes strategies that were put in place for one reason, could also solve other issues concurrently;

The problem was my uncle was going down [to the chemist] ... and just collecting whatever medication he could ... In organising the Webster-pak we actually solved three or four other medical issues. Because he was missing medication, he was double dosing on medication. All because of the dementia. So the Webster-pak actually helped us solve many, many issues. (Carer_001)

3.3. Risk ramifications

Nurses in particular were seen "to make black and white a disease that is grey". While the primary reason for this concern was seen to be the health of the person with dementia and those around them, the additional layer of responsibility that nurses experienced placed further onus on this group to ensure that they and their patients were not at any type of risk;

Nurses have become so - pardon me - risk adverse that we're no longer giving people a go, because we're afraid that if it fails it's impacting on us and we have to answer to whomever for that. (Staff_009)

In considering how to act on an identified risk, some participants spoke about not only the risk of inaction, but the risk of action. It was perceived that very little attention was given to the risks that may be generated by acting to keep someone safe, with most attention placed on managing the identified risk only;

Often [nurses] do things like, somebody will leave the gas on once and all of a sudden you've got processes in place where they've put something in

to actually disconnect the stove and the client will never be able to cook on a stove again. So they created a whole lot of other risks because then they can't eat appropriately. (Staff_002)

In addition, it was believed by a number of individuals that “wrapping people in cotton wool” was counterproductive, and would facilitate a quicker decline for those living with dementia;

He's quite capable of [catching public transport on his own]. So I figure if I stop him doing that or go with him all the time ... he's just going to lose that much more quickly. (Carer_022)

People with dementia in particular spoke of the negative ramifications and often unintended consequences relating to the management of their cognitive and functional decline. For some they could see that activities or chores had been taken from them or redone leaving the person with dementia with a sense of purposelessness;

The thing that I feel is that - and as much as I love [my husband] - I feel as though he has taken things away from me ... he is a perfectionist and if something is not quite right, then you - he will fix it up or something. It might be a minor thing that doesn't really matter. (Person living with dementia_007)

Another example of this was lack of service utilisation or provision; this would often lead to increased carer stress. This risk could be significant if the carer was not getting enough support to facilitate the continued home living arrangements;

I was getting to the stage where I just couldn't keep him safe. I was so exhausted. I think for a good 18 months. I could not allow myself to sleep ... I locked us in our bedroom area at night, which I know is totally unsafe in many ways. I would lock it so that we only had access to the bedroom and the ensuite. It was so that if I did fall asleep, firstly, he wouldn't just wander off, and that I just knew that - my fear always was what if he gets out or away? Or does something when I'm not aware of it? (Carer_008)

This was further echoed by staff members who recognised that stressed carers could not provide adequate care for the person with dementia, also hastening placement into residential care and creating other risks for all involved;

[The carer is] clearly exhausted as well, which is another risk. The carer stress is huge for people that take on those roles (Staff_001)

3.4. Competing conceptions of dementia

Participants observed that views and perceptions of dementia varied between and within groups of people, adding a level of intricacy into a situation which was already complex. In particular, the issue of capacity after a diagnosis of dementia was seen to be difficult, as it was often assumed – particularly by nurses – that those who have a diagnosis by definition had lost their capacity to make decisions about not only their health but other aspects of their life;

I still struggle almost every time with some staff, is understanding that just because someone might have dementia or some other form of cognitive impairment, it doesn't therefore mean that they have lost every right to make any decision making themselves. So that person might have dementia, but might be very clear about making a choice that is their right, or even if they remain capacity and they're making very unwise choices which puts them at risk, it's still their choice (Staff_017)

The knowledge and understanding of those around the person with dementia was also important, with a lack of understanding of dementia and its effects on a person significantly affecting how the person with dementia is cared for, and the services they accessed;

The lack of understanding from the family as well, in terms of - well why is Mum behaving like this or she won't do what we ask ... they can't

recognise that if Mum says no to something, she doesn't really understand the consequences of saying no (Staff_003)

Given the wide range of trajectories and behaviours associated with dementia, some participants indicated how the approach to each individual must be grounded in their circumstances and personal context so that it fit that individual's situation and symptoms;

Dementia for one person is not the same dementia with another. How you deal with it with one person is not the same as you deal with it with another. There's no cookie cutter, it's all got to be tailored and customised (Carer_001)

People living with dementia spoke of the restrictions put in place when the diagnosis of dementia was given; for many it meant that activities they had done their whole lives were taken away from them overnight;

I was 50 then, I lost my job as well and, in retrospect now, I know that if they'd made reasonable adjustments, I could have kept my job (Person Living with Dementia_002)

3.5. Acceptable risk and enablement

The concepts of acceptable risk and enablement were prominent in participant's narratives – particularly for people living with dementia and carers. This view emphasised that risk was an accepted part of everyday life, and that this did not change simply with a diagnosis of dementia;

She would be safer in full time care, but we all would. We just choose to not live there. We choose to live our life instead. Everybody would be safer locked in a secure environment. They're never going to get run over by a bus. If they fall over somebody's there to pick them up ... but we choose not to live like that. (Carer_003)

People living with dementia in particular discussed the positive sides of taking what they saw to be acceptable risks. The independence continuing these activities provided often not only improved their mental wellbeing, but the actions themselves (such as walking) assisted in the maintenance of the physical wellbeing. If they ran into difficulties, the people living with dementia often had strategies in place to assist them in continuing with the behaviour, or resolving the issue;

I go walking on my own ... and I don't call it wandering and I don't get medicated for it. Even before dementia occasionally I got lost. So, when I get lost, I ask for help. Or someone sees I'm lost and helps me. I know that down the track, it might be more dangerous for me to go walking on my own, but for now, it's an acceptable risk in my opinion. (Person Living with Dementia_002)

Some participants spoke about the situations in which enabling people living with dementia and/or their carers had provided unexpected benefits or outcomes. One participant told of how her aunt and uncle had an additional 9 months at home with each other that they would not have had, had she listened to the health professionals involved in her uncle's care;

Another example was the day my aunt decided she was going to bring [my uncle] home, and my head is just saying no this is not going to work. We had the professionals saying no you can't do this and I just said to her, okay I'll let you do it. She took him home and it was nine months. Nine months that she would have otherwise not had with him. (Carer_001)

This sentiment was echoed particularly well by a staff member, who indicated the need to allow people living with dementia and carers to try and live their lives the way that they wished – and that health professionals don't always have the right answers for individuals in this situation;

You've got to give the family and the client a bit of a chance to succeed or fail and sometimes we can be proved wrong and that's not a bad thing. That's good for us to know that we don't have all the answers. (Staff_009)

Finally, the importance of meaningful activity and a purpose to one's life was discussed as a point of priority. This was seen as fundamentally important, and a way to assist in arresting the progress of the disease as well as improving quality of life;

Well you need a reason to get out of bed every day, trust me ... the more active people are the better they cope with their symptoms. It seems that their functional capacity is better for longer. They're happier. They've got that sense of purpose. They really have got meaningful activity. (Person living with dementia_002)

4. Discussion

This paper examined the differing conceptualisations relating to risk in the context of dementia care for five groups; people living with dementia, carers, older participants, registered nurses and staff in managerial roles in a community nursing organisation, focussing on their construction of risk based on their lived experience. The complex nature of risk in dementia care was reflected within and across each of these groups, not only in risk identification and management, but even in how dementia is understood and the ramifications of risk. Furthermore, the theme of enablement and the associated concept of acceptable risk was prominent within the narratives, however implementing these ideals – particularly by health professionals – was a tension present for people living with dementia, carers and health professionals alike. This is the first study that asked older individuals without significant dementia experience about the risks involved for people living with dementia.

Differing contextual factors such as culture, personal preferences and 'risk appetite' were acknowledged as being part of everyday life, and paramount to providing person-centred care in the dementia context. Therefore, viewing a potential risk in the context of the individual, their life history and previous proclivities was seen as important to fully understanding the perceived risk, but also the repercussions of acting or not acting to mitigate the risk. It was this ability for carers to see potential risks in context that made it difficult for some to remove meaningful activities from the person they cared for as they had perspective relating to activity for that individual. In addition, it is a lack of contextualised understanding that facilitates the proliferation of unintended consequences of risk, and the objection to 'excessive' risk-management often expressed by people living with dementia.

Participants in this study identified many different risks that affected a range of different people, from the person living with dementia, to the carer, health professionals and the public. A minority, however, were identified by all groups in this study. Generally, the risks identified by all groups – with the exception of social isolation and dressing – were those that had the potential to impact significantly not only on the person living with dementia but those around them (including the public). Overall, the risks that were identified by each group, however, clustered around the function that group had in relation to the person living with dementia.

Previous research has found that health professionals who work with people living with dementia tend to focus on the physical risks to those in their care (Clarke, 2000; Gilmour et al., 2003; Robinson et al., 2007). This was reinforced by the findings of this study which showed that risks such as medication, food and nutrition, cooking, falls and hygiene were the most prominent risks identified by this group. Furthermore, previous research has found that carers focus on risks relating to the change in their relationship with the person living with dementia, and while this was also supported in this study through the discussion of issues such as responsive behaviours (e.g. aggression,

apathy), carers also discussed other risks that had ramifications for themselves and the person living with dementia, such as driving, cooking, and carer stress (Robinson et al., 2007). People living with dementia themselves tended to focus on the day-to-day repercussions of living with dementia, of prominence being issues such as social isolation and driving. This is supported by other recent research in the area which indicates that daily activities, socialising, and mental health were of prominence in this group (Stevenson et al., 2017 #188), but is slightly different from other previous research that indicated that it is the loss of identity that people living with dementia identify as a risk (Robinson et al., 2007).

This paper identified that many individuals involved in the care of people living with dementia gauge risk based on the diagnosis of dementia rather than the capacity of the individual. This reflects findings of previous research in health professionals such as community nurses (Carr, 2010), however this study has found that this phenomenon was also taking place among some carers and family members. More than ever before, community nurses are now being required to perform more tasks under increasing time pressures. Further, their workload comprises of more complex patients, without necessarily having the formal training into the varying types of dementia subtypes and/or strategies to maintain independence, let alone in enabling individuals to maintain independence. In addition, placements for nurses within their tertiary education tend to focus on acute care settings where supervision is high and decisions made often by more experienced and knowledgeable individuals (e.g. senior nurses, doctors) (Happell and McAllister, 2014). This is vastly different from the context of community nursing, in which the majority of healthcare is delivered by a single nurse and decisions made autonomously or by remote support from others. Together these findings suggest that further education is required not only for community nurses but also carers and family members to facilitate a deeper and more comprehensive understanding of the various forms of dementia and their trajectories. This will assist individuals to understand the fundamental nature of the shifting capacity of the person living with dementia and the potential benefit from allowing them to make informed and person-centred decisions about their current and future care.

As with previous studies (Manthorpe and Moriarty, 2010; McKeown et al., 1999), it was a perception of staff, carers and people with dementia that a significant portion of those working professionally in this space – particularly community nurses in the field – desired for the complete elimination of risk for the person with dementia. This perspective, however was also seen to hasten cognitive decline and ignore the varying perspectives individuals have on risk in ordinary life and the banal but daily risks that people place themselves in during their everyday activities. This perspective also ignores that many people living with dementia in the early stages of disease are capable of recognising deficits within themselves and implementing strategies to manage them, as demonstrated in this study. As with previous research (Clarke et al., 2009), the complexity of risk in dementia care was a prominent narrative from all participant groups within this study. The concepts of acceptable risk and enablement and their unexpected benefits and outcomes were reinforced particularly by people living with dementia and carers. Ensuring that the person living with dementia retains meaning and purpose within their life was seen as one fundamental way in which the progression of the disease could be slowed and allowed for not only people living with dementia, but carers to improve their overall health and wellbeing.

Finally, the findings of this research must be interpreted in light of the limitations. While significant effort was placed into recruiting individuals living with dementia, participants were a relatively small group of somewhat recently diagnosed individuals. In addition, the generalisability of this research is limited given the number of individuals who took part, the health care and social context of Australia, and the focus on the nursing organisation in which the professional recruitment predominantly took place. The focus on varying

perspectives – including the addition of older individuals without significant dementia experience – however strengthens the findings and provides new information that has not been reported elsewhere.

5. Conclusion

Risk is a contextual concept, which varies between and within individuals. The complex presentations, trajectories and manifestations of the varying forms of dementia heighten the need for a contextual response that is based not only in a detailed understanding of the disease itself, but also the person, including their history and preferences. This has the potential not only to improve quality of life for the person living with dementia and their carer, but possibly to also slow the progression of disease. Understanding the differing perspectives of risk pertaining to dementia will facilitate a movement towards truly person-centred care, and may enable people living with dementia to remain in their own homes for longer, should it be their wish, and provide them with dignity and choice in their care. This paper highlights 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.

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