

**Spontaneous concerns about risk and abuse reported
by people with dementia and their carers.**

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Abstract

Purpose

To look at concerns about risk/ abuse expressed spontaneously by people with dementia (PwD) and their carers in narratives describing their journeys with dementia.

Method

Thirty-five narratives were elicited from PwD, carers of PwD and couples where one partner was living with dementia as part of a study on the impact of producing narratives on PwD and their carers. Participants were found to allude to risk/ abuse, or specifically mention thoughts on risk and abuse in their narratives. A secondary analysis of the theme of risk/ abuse is reported here.

Findings

Concerns about risk/ exploitation were often expressed in the narratives, and covered a range of areas including driving; safety in the home; safety outdoors; falls; finances; risk to PwD from others; risk to others from PwD; potential or actual police incidents, and neglect.

Research limitations

The narratives were elicited as part of another project and participants were not asked directly about risk: themes reported here were brought up spontaneously by participants.

Practical implications

In relation to dementia a wide range of risk/ abuse issues is of concern to PwD and their carers, including driving and financial vulnerabilities. PwD and carers are prepared to talk about risk/ abuse when given an opportunity. It is important to investigate and understand experiences and concerns about risk/ abuse if they are to be addressed in health and social care practice.

Originality

The narratives offer unique insights into the concerns of PwD and family carers.

Keywords: dementia; driving; financial abuse; risk; safety; vulnerability

Article Classification - Research paper

Prepublication

Introduction

This paper reports findings from a study funded by the British Medical Association Dawkins and Strutt grant. The aim of the study was to test whether the process of narrative production would be beneficial to people with dementia (PwD) and carers. The study utilized a grand-tour question:

‘I would like you to tell me the story of your life with dementia. The best way to do this is to start from the time that you first became aware that you (or your relative) might have dementia. Tell me all the things that happened one after the other until today. Please take your time and give details. Everything is of interest that is important to you.’

The study was not therefore specifically designed to elucidate insights into participants’ construction of risk/ abuse, nonetheless participants themselves either alluded to risk, or specifically mentioned thoughts on risk and abuse. Journey with dementia was a shorthand term we used to describe an individual’s experience of dementia (“the story of your life with dementia”) and did not/ does not imply that there is one journey with dementia: each person’s experience is unique.

In this paper we have taken a broad dictionary definition of risk:

‘Risk – a chance or possibility of danger, loss, injury, or other adverse consequences’. (Fowler, Fowler, & Allen, 1990)

We recognise that there are wide ranging understandings and interpretations of risk/ abuse (Clarke, 2000; Clarke et al., 2009; Taylor, 2006), that risk management is a complex process and that often the people involved in making decisions about risk/ abuse may assess the balance between autonomy and safety differently. However we (as professionals) construct risk/ abuse, we need to take account of the perceptions, beliefs and experiences of PwD and their carers. We therefore focus here on spontaneous concerns expressed by PwD and their carers, set within the context of practice in England.

Background

The NICE-SCIE Dementia Guideline stated that people living with dementia are:

‘vulnerable to abuse and neglect’ (NICE/ SCIE, 2007, p. 15),

and noted the need for people working in dementia services to receive training in adult protection. Similarly, the National Dementia Strategy described PwD as an ‘at risk’ group, citing the risk of abuse;

‘particularly ... through financial exploitation, fraud and theft’ (Department of Health, 2009, p. 49).

In 2010 the Department of Health published 'Nothing Ventured, Nothing Gained': Risk Guidance for people with dementia (Department of Health, 2010).

In a foreword to the document the National Clinical Director for Dementia wrote:

'It is a challenge to tread the line between being overprotective (in an attempt to eliminate risk altogether) while respecting individual freedoms. The trick is giving people the opportunity to live life to the full, while at the same time making sure they are properly safeguarded.' (p. 2)

More recently adult safeguarding practice in England has changed and been put on a legal footing by the Care Act, which received Royal Assent in May 2014. From April 2015 local authorities are required to set up Safeguarding Adults Boards; make enquiries (or ensure that others do so) if an adult is believed to be subject to, or at risk of, abuse or neglect; arrange for independent advocates to represent adults who are the subject of a safeguarding enquiry or a Safeguarding Adult Review (SAR); and work with appropriate partners to protect adults who are experiencing, or are at risk of experiencing, abuse or neglect (Department of Health, 2016). Six principles of safeguarding (Social Care Institute for Excellence, 2015) are recognised:

1. **Empowerment:** People being supported and encouraged to make their own decisions and informed consent.
2. **Prevention:** It is better to take action before harm occurs.

3. Proportionality: The least intrusive response appropriate to the risk presented.

4. Protection: Support and representation for those in greatest need.

5. Partnership: Local solutions through services working with their communities... (Perhaps partnerships with people with dementia and their carers/ family members might be influential here.)

6. Accountability: Accountability and transparency in safeguarding practice. (Social Care Institute for Excellence, 2015, p. 28).

Whilst welcoming the statutory requirement to 'safeguard adults at risk', numerous commentators have argued that this legislation is overdue (many English Local Authorities had already developed Boards and procedures/policies), and does not go far enough, especially given the lamentable record of prosecutions in cases of severe abuse and neglect.

Surrounded by this changing legal context are PwD and their carers, yet knowledge of the views of PwD and carers about risk and abuse is limited (Daniel, Cross, & Sherwood-Johnson, 2014; Mysyuk, Westendorp, & Lindenberg, 2016). Morgan, a person living with Alzheimer's disease, described her personal view as being that there are risks to people living with dementia from the point of diagnosis onwards and that they need to be supported to find ways round them, and to carry on with their lives (Morgan, 2009): otherwise she felt they might give in to the disease. The Nuffield Council on Bioethics Report on dementia pointed

out that people deemed to have capacity can choose to make decisions which others might regard as risky, but that people who are judged not to have capacity may have their decisions overruled by others, arguing, in relation to risk, that the decision is not in their best interests (Nuffield Council on Bioethics, 2009a). The Nuffield Council Report emphasizes the need to consider both risks and benefits in assessing risk, in order to avoid an approach biased towards decisions which appear to minimize risk, but which may be in the interests of others, rather than the interests of the person living with dementia (Nuffield Council on Bioethics, 2009b).

We report the concerns about, and experiences of, risk and abuse voiced by PwD and the carers of PwD who produced narratives of their journeys with dementia in a study of the therapeutic effect of producing a narrative (Benbow & Kingston, 2016). Our aim within this paper is to offer a secondary analysis of the data, in order to understand the concerns of PwD and their family carers regarding risk and abuse, as expressed spontaneously in their narratives.

Method

The project was granted ethical approval by Staffordshire University Ethics Committee¹. PwD and the carers of people living with dementia were recruited

¹ Please note this study commenced while the authors were based at Staffordshire University and the project was subsequently transferred to the University of Chester where it was completed.

through third sector organisations, and produced a spoken or written personal narrative of their journey with dementia, either on their own or as a couple, when both partners wished to be involved jointly. Spoken narratives were transcribed verbatim and returned to participants for checking. All narratives were analysed thematically using a qualitative analysis computer software package (NVivo) (Bazeley, 2007; QSR International, 2011). The full thematic analysis is reported elsewhere (Benbow & Kingston, 2016): this paper reports a secondary analysis of one theme, risk/ abuse/ concern about vulnerability.

Results

There were fifteen carer narratives; six couples narratives; and fourteen PwD narratives, giving a total of 35 narratives involving 41 individuals. Table 1 gives demographic information about the participants and Table 2 lists sub-themes within each category of risk/ abuse.

Driving was the area most often highlighted in terms of risk and was addressed in the narratives of six carers, five couples and three PwD. The following quotations illustrate their concerns:

'B. kept getting out of his seat belt and standing up on the bus ...' (carer)

'He was threatening to jump out of the car, he did, he was banging on the door ...' (carer)

'he lost control while driving his car ...' (carer)

'I came to the traffic lights at the end of the road and I had to stop and think, what does that signal mean?' (PwD)

'I couldn't see any need for me to slow down at all ...' (PwD)

Safety in the home was a concern voiced in three carer narratives, three couples narratives and three PwD narratives. This subtheme included concerns about kitchen safety, smoking cigarettes and taking medication; for example:

'she leaves doors open ...' (carer)

'I thought I'd knock the kettle off ...' (couple)

'several times she had probably not only had one dose, she had probably had three doses ...' (couple)

'leaving the gas on ... couldn't turn the electrics off ...' (couple)

'he took the cigarettes away ...' (PwD)

Safety outdoors (excluding issues specific to driving) was another subtheme, and featured in the narratives of one carer, two couples and three PwD:

'if he sees a car he will step into the road to stop it to give him a lift ...' (couple)

*'a fear that if you do go out you might be ripped off ...' (in relation to taxi fares)
(PwD)*

Falls may occur within the home or outside and were mentioned by two carers, two couples and one PwD:

'he fell ... and broke his hip and shoulder' (carer)

'we were in danger of falling down the stairs...' (couple)

'the floor dissolves ... on the staircase ... and I come down on my bottom' (PwD)

Carers, in four narratives, and one couple, spoke about the risks to the person with dementia from others, a risk that was present in care homes as well as when the person with dementia lived in their own home:

'there has been a couple of times he has had a slap across his arm' (carer)

'(another resident of a care home) came in and they started to fight' (carer)

In one case the carer told how:

'(relative) rang up (social services) to complain I was neglecting (wife)'.

Similarly three carers raised concerns about the potential risk to the carer/ family posed by the person with dementia:

'he got quite nasty' (carer)

'it was menace, menace... (towards carer)' (carer)

'you worry in case he loses control (with grandchildren)' (carer)

Nine sources referred to incidents of possible or actual abuse and the text (with identifying features removed) is quoted or summarised in Table 3. In the incidents attributable to family carers, the narrative context was always that of the carer feeling guilty about what they had done. One incident involved the carer slapping their partner. In another incident a member of the family contacted social services and alleged that a husband was neglecting his wife who had

dementia. In a further incident the person with dementia was verbally abusive to relatives with the implication that this might lead on to physical abuse, and a incident was described when a carer felt herself to be at physical risk from her partner.

There were four incidents of potential financial abuse or theft. One carer described relatives taking money from his wife's account without permission. Another carer described money going missing from her relative's house and implied that, although she knew who had done it, she had taken no action. A third carer described an incident when a bogus caller had accessed her relative's home but the family could not be sure what, if anything, had been taken. Another carer described children from the locality coming into her relative's home and stealing food:

(children) *'they were emptying the house of food ...'* (carer)

An additional financial risk described was that the person might be vulnerable to pressures or scams, for example:

'ring this free number and you can get into draws ...' (carer)

Discussion

This study has a number of limitations that must be acknowledged. The project was not designed to explore the perceptions of risk and abuse of PwD and their carers/ family members. Those taking part developed their own narrative

accounts of journeying with dementia, and it is likely that more people might have expressed concerns about the areas of risk identified here if they had been asked specifically about them. Numbers of participants were small and some people were interviewed as couples, which might influence the topics they chose to talk about. For these reasons it is important to recognize that concerns about risk, exploitation and abuse are common amongst PwD, who may have insight into their own vulnerability, particularly in the early stages of their illness, and amongst their carers/ family members. Similarly, bearing in mind the limitations of study design and the small numbers, there was a broad range of concerns about risk, exploitation and abuse. Physical abuse of the person with dementia was a topic predominantly raised by carers, but there was also concern about the risks to others posed by some PwD. Indeed, some carers are themselves vulnerable. They may assume a caring role imperceptibly over time, without having the opportunity to give informed consent. Consequently they may feel that they have no alternative to caring for their relative, partner or close friend – perhaps reflecting filial obligation or filial piety (Finley, Roberts, & Banahan, 1988; Stuifbergen & Van Delden, 2011). Health and social care personnel may label them carers without any exploration of what that means or where it might lead.

In clinical practice risk associated with driving can be difficult to assess and manage and there is concern that friends and relatives may not give an accurate picture of a person with dementia's driving ability (Wilson & Pinner, 2013), so the concerns about driving risk expressed in the narratives are noteworthy, although

some involved the person with dementia's behaviour when someone else was driving. It is therefore important that health and social care professionals consistently explore driving and its potential risks in their work with PwD and their families.

It is interesting that financial risks and abuse figured prominently. Samsi and colleagues carried out an online survey of staff of English Alzheimer's Society groups: almost half the participants reported encountering cases of financial abuse over the previous 12 months (Samsi, Manthorpe, & Chandaria, 2014). There is concern that older adults are at risk of financial abuse and that, within the older adult population, people with cognitive impairment or dementia (Davidson, Rossall, & Hart, 2015) or with diminished capacity e.g. dementia, depression, mental illness (Bagshaw, Wendt, Zannettino, & Adams, 2013) are at greatest risk. In connection with this increased risk, Darzins and colleagues (Darzins, Lowndes, Wainer, Owada, & Mihaljcic, 2009) pointed out that other people are more likely to be involved in the financial affairs of people with cognitive impairment/ dementia and the person concerned may be less likely to be aware of abuse and perhaps also less able to take steps to stop it. Darzins et al. also pointed out that, because professionals are more likely to be involved with people with dementia, financial abuse in this group may be more likely to be recognized and reported: this may not, however, be true of scams and electronic crime (Manthorpe, Samsi, & Rapaport, 2012). The Alzheimer's Society has drawn attention to the vulnerability of people with dementia in respect of their

finances, by virtue of the fact that they are likely to need support in managing financial affairs as their condition progresses (Alzheimer's Society, 2011).

Conclusion

The narratives offer unique insights into the concerns of PwD and family carers. Driving is an area of major concern, and we suspect that health professionals do not always recognise its importance to families as a potential risk area. Financial abuse was also commonly raised in the narratives. Taken as a whole, our findings suggest that professionals should not feel constrained in raising the issue of risk and abuse when working with older people receiving care and support and their family carers. The data clearly suggests that these issues are high on their list of concerns, and it is incumbent on health and social care professionals to enable PwD and their carers to express their concerns and also to ensure that they are addressed.

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Table1: Demographic information on participants

Variable	People with dementia (N=20)	Family carers (N=21)
Age range (mean age)	56-89 years (74)	29-87 years (67)
Gender		
Men	60%	19%
Women	40%	81%
Marital status		
Married	70%	86%
Widowed	25%	14%
Not known	5%	
Self-reported/ carer reported diagnosis of person with dementia		
Alzheimers disease	35%	52%
Dementia (unspecified)	45%	19%
Vascular dementia	0	10%
Other	20%	19%
Early onset dementia	20%	24%
Relationship of carer to PwD		
Spouse	Not applicable	81%
Mother/ Mother-in-law	Not applicable	14%
Non first degree relative	Not applicable	5%
Living situation of PwD		
Living alone	15%	Not applicable
Living in community with relative	65%	Not applicable
Living in a Home	20%	Not applicable

Table 2: Table listing sub-themes within each category of risk/ abuse

Theme	Sub-themes
Driving	<p>The PWD's driving</p> <p>The PWD's behaviour while someone else is driving</p>
Safety in the home	<p>Kitchen safety</p> <p>Lack of security doors/ windows</p> <p>Stairs and fall risk</p> <p>Cigarettes and fire risk</p> <p>Medication risk</p>
Safety outdoors	<p>Road safety</p> <p>Risk of being 'ripped off' (shops/ taxis)</p> <p>Getting lost</p> <p>Vulnerability eg using cashpoint</p>
Financial	<p>Being taken advantage of by others eg children taking things; being persuaded to buy things; being 'ripped off' because of not understanding money.</p> <p>Misuse of credit cards by family members.</p> <p>Money going missing.</p>
Falls	<p>Inadequate supervision by others.</p> <p>Stairs as a risk.</p> <p>Carrying things as a risk.</p> <p>Visuo-spatial problems.</p>
Risk to PWD	<p>Verbal abuse.</p>

from others	Physical abuse.
Potential or actual police incidents	Theft. Bogus caller. Malicious phone call.
Risk to others from PWD	Worry about PWD losing control. Over-reacting. Will verbal abuse turn physical?
Neglect	Family accusing carer of neglect of PWD.

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Table 3: Descriptions by carers in their narratives of incidents of possible/ actual abuse

Category of abuse	Quotations/ summaries
Verbal abuse	<p>'I always used to think I was a patient person, but this last few months you know I will admit to you I have even shouted at him ...'</p> <p>'I know I have shouted at him'</p> <p>'I hate – I am afraid I shout at him sometimes – yes I do – I hate it ...'</p> <p>'I know it sounds nasty – but if I actually do shout at her, quite loud toned voice, she will stop doing what she is doing...'</p> <p>'I shout at him sometimes ...' (described in a couple interview)</p>
Financial abuse/ theft	<p>'So I gave him the two cards ... (my wife) had about £8000 in her bank, and I found out later ... (that) (two relatives) had also made a payment of £50.00 a month out of (my wife's) bank book to carry on, but I found that and I have stopped all that.'</p> <p>'I can't tell you how much money has been lost, over not this because I have put things in place now, but 2008, I just really don't want to go down that road, because I don't know</p>

	<p>where it has gone’.</p> <p>‘it was a bogus caller ...’ (She) said ‘well he hasn’t taken anything anyway because I hadn’t got anything lying about’, but we know that she does leave money here and there, so he could well have done.’</p> <p>‘she was having children going into see her from the Council Estate, which was quite a way away and they were coming and they were emptying the house of food – but we didn’t know’.</p>
Abuse of the carer by the person with dementia	<p>‘the three of us were getting verbal abuse and he got quite nasty ...’</p> <p>Carer described an incident when she felt menaced by her husband and locked herself into a room until he had calmed down.</p>
Physical abuse	<p>‘I do have my flare-ups and I shout at him and there has been a couple of times he has had a slap across his arm, you know, when I have been a bit run down ...’</p>
Neglect	<p>‘(a relative) rang up (the social worker) to complain that I was neglecting (my wife)’.</p>

Prepublication