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Risk Management Dilemmas in Dementia Care

Risk management dilemmas in dementia care:

An organisational survey in three UK countries

Abbreviated Title: Risk management dilemmas in dementia care

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ABSTRACT

Aims and Objectives

The overall project aimed to understand the variability of the construction of risk in dementia care from the perspective of the person with dementia, family carers and practitioners with the intention of developing negotiated partnerships in risk management.

Background

Risk management can result in a 'safety first' approach to care practices, but this may be disempowering for people with dementia.

Design

This paper describes the results of the first stage of the study: a survey to service managers or equivalent in health, social and voluntary sector care organisations in three countries of the UK.

Methods

Data from this stage was collection by postal questionnaire (n=46).

Results

Risk was portrayed as a multidimensional concept and clustered around three themes: 1) Risk and Independence, 2) Risk and Resource, and 3) Organisational Risk Management.

Conclusions

Very wide understandings of risk are identifiable, ranging from avoidance of physical harm through to managed risk taking to improve quality of life, and to an appreciation

of the impact of organisational and professional patterns of behaviour resulting in

harm to the person with dementia.

 Relevance to Clinical Practice

Obtaining information about the perspectives of others may help to illuminate some of

the dilemmas experienced by staff in this study, and the development of risk

assessment frameworks may assist staff to resolve some of these.

Acknowledgement

Key Words:

Risk management, dementia, survey

Dilemmas in risk management in contemporary dementia care:

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BACKGROUND

Risk is understood in a variety of ways (Althaus 2005) but at its heart are issues of uncertainty of future outcomes from actions. It very often suggests negative outcomes (as in the work of Beck 1992, and the World Health Organisation 2002) yet positive risk taking is often admired and is recognised as being essential to a rewarding engagement with life and in successful business management (Heyman 1998). Douglas' work highlights that risk is culturally embedded, meaning different things to different people and in different societies and contexts (e.g. Douglas 1994). For example, in dementia care, as with other areas of enduring health and social care, there are marked differences between the dominant knowledge of professional and lay carers (Clarke & Heyman 1998) resulting in competing and different priorities in managing care. However, 'risk' is a primarily a preoccupation of westernised, more developed countries which have highly regulated health and social care systems and is less culturally embedded in developing countries.

In health and social care practice in westernised countries, risk is central to professional practice, assessment and decision making (Manthorpe **et al**. 1995, Alaszewski **et al**. 1998, Heyman 1998). This centrality is reflected in the growing emphasis on risk in UK policy (e.g. Department of Health 2007). Theories of risk are often complex and challenging to translate into professional practice, with Titterton (2005) describing professionals as having 'to operate within a patchy and ill-defined context' (p. 33). This often leads to a resistance to engage with risk in day-to-day

practice and prevents positive risk taking because of the organisational and professional culture in which staff and managers practice, and in turn perpetuate. Langan (1999) similarly writes that 'mental health professionals commonly operate in conditions of uncertainty where risks are unclear and ethics dilemmas are rife' (p. 154). Titterton (2005) argues that the 'safety first approach' that dominates contemporary health and social care practice is problematic since:

- It ignores the other needs of vulnerable people

- It denies them the right to choice and self-determination

- It leads to a loss of a sense of self-esteem and respect

- It can lead to a form of institutionalisation with the loss of individuality, volition and an increase in dependence

- At its worst, it can lead to the abuse of vulnerable people. (p.15)

The National Audit Office (2007) identified that value for money is not being achieved by UK dementia care services: for example, in 2006, only 56% of Community Mental Health Teams (CMHT) for people with dementia were integrated, the opportunity to 'refer on' to other specialists was restricted because of a paucity of service options, and most teams believed that acute hospital nurses lacked knowledge in caring for people with dementia. In this context, approaches to risk management are particularly poorly developed and described, with many risk assessment tools being adapted from adult mental health services (Clarke **et al**. 2004) and guidance on risk management in mental health (Department of Health 2007) omits reference to dementia care. Indeed, where assessment frameworks are available, they tend to emphasise the importance of professional understanding with interventions geared to

emphasise 'safety' and 'security'. For example, the Department of Health (1997) outlined the components of a risk assessment as being: self-neglect, exploitation, wandering, abuse, injury, isolation, financial loss, damage to property and risk to others. Whilst, at a prima facie level this may be understandable, it is an inadequate summary as the focus on loss and challenging behaviour disempowers people with dementia and fails to identify the real meaning of risk for that individual. It is an approach that also fails to promote risk taking, yet risk taking is something that Titterton (2005) describes as: 'a way of enhancing people's lives; recognising the importance of psychological and emotional needs, as well as physical needs; promoting choice and autonomy for the individual; valuing the individual, irrespective of whether they live in community or institutional settings; promoting the rights of vulnerable people and their carers, while accepting that these will sometimes be in conflict' (p. 16). However, the differing approaches of understanding risk as problematic and as contributing to quality of life both fail to take the interplay between self and society into account (Clarke **et al.** 2006; Clarke 2008).

The study that is in part presented in this paper aimed to develop a framework of risk assessment that is grounded in the experience of risk as constructed by people with dementia, their close family supporters and professional groups involved in community support. This approach promotes the notion of partnership that is central in the contemporary climate of dementia care research and practice development, and provides a voice in the construction of risk for all those involved in the process. It recognises the dilemmas and contradictions inherent in risk management when the focus of risk is widened beyond the avoidance of physical harm.

STUDY DESIGN

Aims

The overall project aimed to understand the variability of the construction of risk in dementia care from the perspective of the person with dementia, family carers and practitioners with the intention of developing negotiated partnerships in risk management.

These aims were met by the following four objectives:

1. To identify the multiple understandings of risk by people with dementia, family carers and practitioners;

2. To assess risk construction and management in different locations of care, i.e., domestic home, day care, residential care, specialist continuing care and acute assessment care environments;

3. To explore the impact of risk assessment on the person with dementia and their family, in terms of quality of life;

4. To develop a risk assessment and management framework for use by practitioners in partnership with people with dementia and their families.

The project used an action research design with two distinct components:

1. A data collection phase, including an organisational survey of current risk management, and interviews with 55 people with dementia plus nominated family carers and practitioners, located within three project sites in north-east England, north-west Wales and south-east Scotland, and conducted in a number of care environments (see also Clarke **et al.** 2004; Keady **et al.** in press).

2. A practice development research phase, located in north-east England, working

    closely with practitioners (see also Clarke **et al.** 2006).

The study received Multi-Research Ethics Committee approval in January 2003 (ref:

MREC/2/3/74).

Methods

This paper focuses specifically on risk dilemmas identified by respondents to the

organisational survey of current risk management. This stage of the study aimed to

identify the understanding of risk by practitioners in the context of their practices and

policies. Thus only the methods for this first stage of the research project will be

reported in detail.

As the initial component of the first phase, a questionnaire was designed to gauge

contemporary risk management approaches for people with dementia.   The

questionnaire included a consideration of: the service provider's risk assessment

guidelines and documentation, the nature of the service provision and client group,

any identified risk dilemmas, markers of risk management (e.g. accidents). The data

was collected in 2003 and is reported in Clarke **et al.** (2004). Despite the subsequent

policy interest in this area, continuing difficulties are reported (e.g. National Audit

Office 2007) and it is reasonable to regard the data reported here as of continuing

relevance to the welfare of people with dementia. This paper focuses specifically on

the risk dilemmas identified by respondents in written responses to the following open

question in the questionnaire:

"Providing services for any client group can create risk dilemmas in which

service providers find themselves with difficult decisions to make about care.

Please describe some of the risk dilemmas that you and your organisation are

faced with – you may use (anonymised) case examples to describe these".

The purpose of the questionnaire was two-fold: firstly, to provide information on

current practices around risk; secondly, to make contact with practitioners who may

be willing to act as gatekeepers to sampling for the interviews with people with

dementia. Accordingly, the questionnaire was strategically targeted to key personnel,

rather than ensuring comprehensive distribution to all services. Thus, within each

location, the managers / service leads of services for people with dementia were

identified within a range of organisations, including NHS Trusts, Social Services

Departments, Voluntary agencies, Independent sector, Primary Care Groups and

Local Health Boards. In total, 182 postal questionnaires were distributed. After two

weeks, non-responders were contacted by telephone to ensure that the questionnaire

had been received, and to offer telephone completion of the questionnaire if preferred.

In Wales, the questionnaire was translated into Welsh and available in the language

preferred by the respondent.

By region, return rates were NW Wales = 18/101 (18%), NE England = 15/50 (30%),

SE Scotland = 13/31 (42%), and by organisational type rates were NHS = 15/44

(34%), Social Services = 6/44 (15%), Voluntary Sector = 10/25 (40%), Independent

Sector = 13/68 (19%), while two questionnaires were returned from organisations

which spanned sectors (Mental Health and Social Services; Voluntary and

Independent Sector). Twenty-five percent of the questionnaires were returned overall (46/182). Respondents to the questionnaire were service / home managers (n=28), nurses (Community Psychiatric Nurses, Registered Mental Health Nurses, clinical nurse leads) (n=7), other health care professionals (n=2) and dementia care co-ordinators (n=2). Such a low response rate is disappointing and compromises the ability to differentiate responses between the diverse groups within the sample. It is likely to reflect in part the difficulties of sample identification across multiple agencies and some questionnaires may have reached people who did not feel well placed to respond, possibly because they adopt an uncritical position in relation to risk management in day-to-day work. Whilst this is a poor response rate, it is relevant to note that the dependence on responses by key members of staff made the survey vulnerable to role and staffing changes in organisations and it is unknown how many of the 182 questionnaires that were distributed actually reached the target person.

The data reported here does serve to indicate some of the diversity and complexity of risk management and was used to inform the subsequent interviews in the study. The data is textual data obtained within the context of a postal questionnaire and there was not the opportunity to follow up points and probe further as would have been the case within a qualitative interview. The subsequent interviews in component 1 and the data collected during component 2 of the study, however, provided the opportunity to check the validity of the survey responses and enhanced confidence in the trustworthiness of the data. Indeed, it may have been that the anonymity of a postal questionnaire enabled some staff to disclose their concerns about risk management that they would have been cautious to do in a face-to-face interview.

Data from the questionnaires was entered into an Excel® spreadsheet and qualitative data were analysed thematically. Quotes are used to illustrate the emergent themes and are taken verbatim from the questionnaires.

RESULTS

Thirty-nine respondents (85%) described risk dilemmas faced by themselves and their organisation. These descriptions covered philosophical issues around risk including themes such as choice, rights, independence, capacity, balance, conflicts, and positive risk, as well as organisational factors such as resources, litigation, guidelines and support, and descriptions of particular physical risks. Many respondents identified multiple dilemmas in relation to risk in dementia care, and themes were frequently overlapping and related. Thus risk was portrayed as a multidimensional concept and clustered around three themes: 1) Risk and Independence, 2) Risk and Resource, and 3) Organisational Risk Management. Each of these three themes will now be addressed in greater detail.

Risk and Independence

Respondents described the difficulties that they encountered in trying to balance provision of freedom of choice for the person with dementia, and maintenance of independence and rights, with the need to protect them from harm or negative outcomes. A senior manager in an English NHS Mental Health Trust wrote how the "*encouragement of independence always results in increased risk to the individual*" and a senior nurse working in a NHS acute Trust in Wales asserted: "*risk is an integral part of everyday life and should continue to be so for clients – but at a reasonable level*". However, it is this negotiation and meaning about what constitutes

a "reasonable" level of risk that poses a dilemma for professionals working with people with dementia and their families.

The Director of a voluntary sector organisation in Wales articulated this dilemma in more detail: "*perceptions of what constitutes acceptable risk can often be problematic between managers, staff and family carers – family carers need to keep the person with dementia 'safe and looked after'*". A service manager in an English mental health NHS Trust agreed, saying, "*often carers do not want to accept any risk at all, leading to conflicts in care and approaches*". Another manager – in the English voluntary sector – echoed this statement: "*most residents don't have any insight into any risks that they may be taking with simple every day tasks, and some families expect you to take away the risk completely, which will also take away any independence*". Furthermore, a consultant psychiatrist in Scotland explained that part of the difficulty is the different weighting that families and professionals give to certain risks and whether these risks are manageable. Thus there may be pressure from families – or even medical colleagues not trained in mental health – to move a person with dementia into a residential home, when there is the possibility that person would be able to manage at home with support.

Notions of risk taking were closely linked to maintaining quality of life for people with dementia. In one voluntary sector organisation in Scotland, the practice development manager wrote about engaging people with dementia in activities such as cooking, ironing and swimming. With such activities, she pointed out that "*specific disabilities do create risks of involving people with dementia but we also feel that it is creating such opportunities with their inherent implications for quality of life*

that we should be facilitating". In a similar setting in Wales, a care home manager

reported the dilemma of balancing "*quality of life versus safety, such as walking about*

the home – activities the resident enjoys".

Some respondents focused on the safety or physical harm aspects of risk, when

answering this section of the questionnaire. Several flagged up the risk of wandering,

with a domiciliary care manager in Scotland reporting, "*we get pressure from families*

to lock the clients in when we leave but we refuse to do so because of other risk

factors." Driving, security, medication and meal provision were other risks listed by

participants. Some respondents wrote about the dilemma of knowing the point when

a particular risk had reached an unacceptable level, as illustrated in this quote:

> "People who may not be safe with gas, cooking appliances, heating - when to
>
> cut off gas supply etc. People who are reluctant to accept services but who
>
> may be eating or caring for themselves spasmodically - when to impose
>
> services." (NHS Dementia Care Co-ordinator)

In managing risk dilemmas, a senior clinical nurse described the need to do some

"risk taking" themselves, especially when:

> "Assessing whether the 'safety' of the client living in their house, often alone,
>
> outweighs that of receiving 24 hour care and taking into account what the
>
> client/ carer wants - which maybe different to the outcome of the risks
>
> assessment - conflict of opinions. There can also be different opinions

between the client, dementia sufferer and their carer. Balancing the wants of the client to the safety of the client."

In general, risk was perceived to be an issue that was too complex to be solved, but one in which risks could be managed to achieve a certain balance. It was negotiation of this balance that results in challenge to managers and practitioners. A senior manager in an English mental health NHS Trust describes the enduring and frequent nature of these tensions: *"Restraint and restriction of personal freedom are a daily dilemma"*. The nature of these tensions are highlighted by an NHS Service Manager in Wales in the following quote.

"Falls versus human rights; confidentiality versus carers' wishes; client wishes versus carers' standards; liberty versus sedation; immobilisation versus home support"

Descriptions of dilemmas were very often accompanied by reference to the restricted capacity to respond to such complex situations, and this forms the second theme that was identified.

Risk and Resource

The nature of interpersonal and physical resources that were available was a feature of many of the responses. A mental health nurse in Wales emphasised the need for joint working with other members of the multidisciplinary team to assess and manage risks, so that decisions (and responsibility) do not rest with one professional. A manager within an English Mental Health Trust highlighted that a lack of a multidisciplinary

team approach to risk management can cause conflict and disagreement in teams. Thus where professionals are able to take a team approach to risk and risk taking this would appear to be beneficial to both practitioners and service users.

Several respondents highlighted that lack of resources, especially in terms of staffing, can *"prevent effective and constructive risk taking"*. One service in Scotland reported that service users' identified needs were continuing to be unmet due to delays in accessing resources and services because of staff shortages. A social services manager in Wales wrote of the difficulty of finding skilled workers, and the dilemma of "*keeping people at home when there isn't a residential resource available"*. However, a voluntary sector organisation in Scotland was in the fortunate position of being able to offer one-to-one care for its clients, as highlighted in the following quote.

> "We have 1:1 care and focus on what each individual client wishes to do, for example, we had a male client who became extremely restless if he was unable to go outside, we are in the fortunate position that he was able to leave the building any time with a volunteer for an enjoyable walk around the park. Clients are encouraged to keep up any hobbies, e.g., go golfing, gardening, etc, with volunteers. We also use life story books that clients and volunteers have developed, if any client becomes restless/confused, a quiet corner looking at this is extremely helpful."

Some respondents highlighted that providing care for a person with dementia who has challenging behaviour may put the care workers at risk of physical harm.

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Additionally, other residents or service users with dementia may be placed at similar risk. Several organisations in Scotland highlighted the success they had had in this area, by using outside trainers to guide them in the management of challenging behaviour. A further component of managing risk is this organisational response, and this forms the focus of the following third theme of the findings.

Organisational Risk Management

The respondents were ever mindful of regulations, and health and safety legislation (or at least perceptions of it) was reported as bringing its own dynamic to the area of risk with people with dementia. In one NHS Trust in England, a service manager reported that health and safety legislation "*can inhibit proactive practice as nurses fear litigation*"; and in a voluntary sector organisation in Scotland, a manager commented on the inhibiting impact of health and safety on service users' involvement in activities – "*we have faced instructions before from Health and Safety officers who insist service users cannot be involved in cooking if they are going to eat the results - which rather undermines the purpose*". However, related to this, some respondents reported the need for risk and safely guidelines that are specific to clients with dementia that would "*safeguard both clients and others*". Alongside this is a request for more in-depth training around the management of people with dementia.

Several organisations that responded to the questionnaire emphasised the need for someone to advocate on behalf of the person with dementia in relation to choice, quality of life and risk taking, which is important when there is client / carer conflict. One dementia care coordinator asked, "*Who is most important in providing services – client or carer?*" This is also essential when an individual lives alone and has no

family or friends, as described in the following quote by a Social Services service

manager in Wales: "*Difficulties about making decisions about care and the dilemma*

regarding appropriate representation (no real advocacy service available)".

The impact that organisational culture and risk management may have on someone

with dementia was highlighted by one manager of a voluntary sector organisation in

England as:

> "There is a tendency by purchasers to remove the person rather than the 'risks'
>
> involved. Clients are disempowered and their rights as citizens denied due to
>
> medicalising dementia and collusion of social services."

In summary, professionals working with people with dementia clearly encounter

dilemmas related to risk and risk taking on a frequent basis, and are endeavouring to

work this out in their daily practice. However, there is an obvious struggle to balance

the different elements within their duty of care, to ensure that the person is maintained

in a safe environment, whilst at the same time preserving a good quality of life.

DISCUSSION

There can be few areas of practice that are more complex and contended than

managing risks in dementia care. Some of the risks are very tangible, others much

more subtle. Some risks are visible to certain individuals involved, but not by others.

Indeed, such complexity is to be expected if the cultural specificity of risk described

by Douglas (1994) is accepted. The data presented in this paper portray a complex

system of interconnected decisions and actions with many stakeholders involved.

These stakeholders extend beyond the individual person with dementia to involve professional and non-professionally qualified staff, along with a range of family carers, wider multi-disciplinary teams and organisations, who are themselves guided by frameworks such as health and safety legislation. One challenge is to disentangle these interrelationships, to understand which perspective comes from which stakeholder and how the one impacts on the other. The data reported here are from a sample of service managers (or equivalent) in a wide range of statutory and non-statutory sector providers of dementia care services. As such, they represent the nexus of complex decision making between all the stakeholders. However, it is important to note that these data do not represent the dilemmas around risk that are perceived by people with dementia or carers themselves.

The close association between risk and need means that it is possible to gain an insight into the perceived needs of people with dementia (Clarke 2000; Stevenson 1999). A number of respondents reported the importance of protecting the person from possible harms of a physical nature. These included the possible consequences of wandering, driving and eating adequately among others. Critically though, respondents reported that other stakeholders expected certain actions from them. One example, is being expected by family carers to lock people with dementia into their homes to avoid wandering behaviour. In such situations, the respondents are required to meet the needs of the person with dementia and in addition respond to the perceptions of risk of others (this most often leading to an expectation that risks are removed) (Titterton 2005). This accepts the centrality of risk management to professional practice (Manthorpe **et al**. 1995, Alaszewski **et al**. 1998, Heyman 1998)

and extends an understanding of the complex network of stakeholders that are part of that process.

As in any situation of seeking to meet a need, the resources at the disposal of the practitioner are an important part of their decision making. In the reported study there are two aspects of resource highlighted. One is the resource of other members of a multi-disciplinary team who are able to work together to develop a shared understanding of the risks that the person with dementia is exposed to and can agree actions to modify those risks. The second aspect is the care interventions that can be deployed, and several respondents emphasised that a lack of service resource can result in undue exposure to possible harm through either under-responding or over-responding to a need. In under-responding, the person with dementia and their family remain in a situation that is judged to be potentially harmful with insufficient intervention to modify it. In over-responding, a higher level of intervention is used than is necessary, resulting, for example, in an unwanted admission to a care home.

In day to day decision making situations, the dilemmas faced by many of the respondents concerned balancing independence and autonomy with exposure to potential harm. This balance requires reconciliation of two basic principles of ethics. The first is the universal duty of good clinical care – the use of expertise to protect the life and health of the people to an acceptable standard. The second is the universal duty to respect the autonomy of people. Clearly, these are the two issues that at times conflict with each other when caring for older people with mental health needs. Very often, the immediacy of the care situation presents multiple and sometimes conflicting avenues of action (Clarke & Gardner 2002). This is what Raines (2000) describes as

an ethical dilemma: 'when two or more ethical principles apply in a situation, that support mutually inconsistent courses of action' (p. 30) and explains the messy practice environment identified by Langan (1999).

Maintaining safety and protection from harm is, in the view of some respondents, insufficient. As promoted by Titterton (2005), it is the proactive practice of promoting activity in order to improve quality of life that was advocated by many respondents, the associated exposure to harm being regarded as a necessary part of achieving engagement, fulfilment and quality of life. These where at times presented as oppositions e.g. 'liberty versus sedation'. The question then becomes "which consequences are we as individuals (be it person with dementia, family carer or staff) and as a society more prepared to accept?". The lack of consistency in which consequences people are prepared to accept, places practitioners and service managers in a very ambiguous position and fuels an inclination to avoid threats of physical harm, even when so doing may compromise the quality of life of the person with dementia.

Some respondents went as far as to suggest that the assumptions that underpin the practices of some service providers and some organisations are quite harmful to the people for whom they care. Wardhaugh and Wilding (1993) sound a cautionary note when they refer to the lack of appreciation of the essential humanity of all service users as underpinning the 'corruption of care'. This initiates a cascade of events and processes that result in organisations delivering care that betrays the standards espoused by caring institutions. Raines (2000) describes how some of the coping strategies used by staff, who find themselves confronted with ethical dilemmas and

'moral anguish', lead them to distance themselves from those they care for. They fail to even recognise the ethical conflicts present and report emotional exhaustion, depersonalisation and negative coping styles – some of the very factors that Wardhaugh and Wilding (1993) warn of as precursors to corrupt care practices. The role of effective leadership, and in particular a vision and purpose in care, is essential to the appropriate use of knowledge to determine the nature of that care.

Reflected in so much of the data reported here, is tension around the rights of people with dementia and the subsequent ethical tensions. Seedhouse (1998) asserts that: 'morality is of such profound importance in health care that it is impossible to understand the nature of health work without also understanding the nature and purpose of ethical reflection' (p.36). Reed and Ground (1997) extend ethical consideration beyond the single clinical decision, to locating that decision in the political dimensions of healthcare relationships.

> "Many of the moral issues which nurses face are not particular events about which single decisions must be made, but permanent features of the relationships and structures within which nurses and patients find themselves."
> (Reed & Ground 1997 p.94)

In conclusion, this account of one component of a larger study indicates that the dilemmas faced by practitioners and service managers in risk assessment in dementia care are indeed complex, and profoundly influence the nature of care available to people. Very wide understandings of risk are identifiable, ranging from avoidance of physical harm through to managed risk taking to improve quality of life, and to an

appreciation of the impact of organisational and professional patterns of behaviour resulting in harm to the person with dementia (somewhat reflective of the positive and negative risk management cycles described in 'Best Practice in Managing Risk', Department of Health 2007). In considering the implication of this study, it is important to acknowledge the limitations. Postal questionnaires give little scope for detailed responses and the 25% response rate is poor. However, it is, therefore, essential that no-one working in dementia care should assume that their own perspective on risk is held by others and, not least, by the person with dementia and their carer. What the data reported in this study does point us towards however, is a range of questions to be posed about risk perceptions in future research and practice. At the very least, obtaining information about the perspectives of others may help to illuminate some of the dilemmas experienced by staff in this study, and the development of risk assessment frameworks that make explicit the perspectives of practitioners, people with dementia and family carers may assist staff to resolve some of these issues.

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