

Using risk management to promote person-centred dementia care

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Abstract

Risk management for people with dementia has traditionally focused on preventing physical harm. However, research has demonstrated that focusing on the physical safety of people with dementia may result in their social and psychological wellbeing being overlooked – the very aspects that are necessary to achieve person-centred care. This article discusses the main challenges for practitioners caring for people with dementia in various settings, and encourages a care approach which enables appropriate risk taking as a way of promoting person-centred care.

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RISK IS AN accepted part of everyday life. Almost everything we do involves some risk, whether it is driving the car to work, crossing the road or participating in activities such as climbing or mountain biking. This article examines the main issues involved in understanding risk in health care, and explores how we can approach risk assessment and risk management with people with dementia in a way that enhances person-centred care. The article encourages us to reflect on situations that we may encounter in many areas of practice.

Risk, harm and dementia

Risk is usually considered in a negative way, as something that should be minimised, if not eliminated, in general healthcare settings (Health Education Authority 1997). The term originates from the Italian word *risicare*, which means ‘to dare’ and was originally considered to be more about choice than fate (Bernstein 1996). In Western society today, the predominant thinking around risk involves ‘the possibility of incurring misfortune or loss; hazard’ (noun) and ‘to expose to danger or loss; hazard’ (verb) (Collins 2016). There has been a shift towards framing risk as something to be avoided rather than embraced. This shift, together with the fear of litigation, motivates many organisations to seek to manage risk by avoiding risks, rather than by taking positive risks.

Repositioning risk as a necessary part of quality of life is essential to person-centred dementia care. This is evident in policy guidance (Morgan and Williamson 2014) and social enterprises such as Dementia Adventure (www.dementiaadventure.co.uk). Kitwood (1997) emphasised the ‘malignant psychology’ that someone with dementia is likely to experience and its detrimental effect on their wellbeing. It is important to recognise ‘silent harm’ in which the person with dementia experiences aspects of life that are important to them being taken away, for example being stopped from cooking, in addition to the risks of physical harm that health and social care staff often identify. These may include the risk of falling or of going missing. Silent harm that subtly takes things away from someone may be difficult to notice, in contrast to recognising harm, for example when someone falls (Clarke *et al* 2011).

Managing risk by attending to physical safety only may lead to (Titterton 2005):

- ▶ Ignoring the person’s other needs.
- ▶ Denying a person the right to choice and self-determination.
- ▶ Loss of a person’s sense of self-esteem and respect.

- ▶ A form of institutionalisation with loss of individuality and volition, and an increase in dependence.
- ▶ Abuse of vulnerable people.

Respondents to a survey inviting them to identify dilemmas in risk management, indicated that they sought to balance independence and autonomy with exposure to potential harm in day-to-day, decision-making situations (Clarke *et al* 2009). Reporting on a qualitative study, Roger (2008) stated: 'Their declines do not put an end to laughter, making meaning, and cherishing important relationships'.

In the nursing care of people with dementia, we encounter the challenge of placing that person, who happens to have dementia, at the centre of our decision making, rather than the dementia, which happens to be one aspect of that person. We may find it helpful to move from thinking about people being vulnerable, and managing their risks and harm, to understanding that there may be situations in which someone is vulnerable. Therefore, vulnerability is part of the context of a situation and not inherent in the individual.

Thinking of vulnerability in this way allows us to consider enabling risks and positive risk taking to enhance quality of life. It also identifies additional ways for us to support people with dementia. We are no longer constrained to managing the person with dementia as a person who is inherently at risk, but can attend to their social and physical environment to provide a supportive environment.

Time-framing is a useful risk concept that helps explain why it is difficult for health and social care staff to focus on the individual (Clarke and Heyman 1998). As practitioners we are educated about the condition of dementia. In our initial and ongoing assessments, we seek evidence of where someone fits into the spectrum of dementia and in our future, or prognostic, outlook we see the progression of dementia. Lay people, for example, the person with dementia and their family, have a knowledge base established from knowing the individual, and seek evidence of the continuity of that individual. They are assessing today against past experience of that individual, not assessing today against a future of many people with dementia.

Consider the case study in Box 1. In this example, Peter draws on his knowledge of his mother's (biographical) background and offers a context in which her behaviour has a person-centred explanation. The only context the care staff were aware of was the pathology of dementia and so they interpreted Peter's mother's behaviour in that context.

Risk assessment

There is an important initiative to improve the patient's experience of health care by reducing harm, mortality rates and adverse events, and improving patient safety. Bodies such as Healthcare Improvement Scotland were established to oversee this initiative.

Healthcare organisations, such as hospitals, work from a risk-averse basis in a tight regulatory framework, placing emphasis on physical aspects of safety and attempting to predict and manage risk using tick-box assessments and matrices (Heyman *et al* 2010). This is essential to reduce the incidence of conditions such as sepsis and to identify individuals at risk of developing them at the earliest opportunity. However, the focus on assessing physical risks and harm has the potential to increase other less tangible harm, often unintentionally, including emotional, psychological and spiritual harm that may adversely affect the sense of wellbeing of the person with dementia (Clarke *et al* 2011).

Kemshall *et al* (1997) asserted that the tick-box mentality of completing risk assessment forms often takes precedence over professional judgement and tells us little about the person 'behind' the diagnosis. Risk assessment formats are 'often negative in focus... with little room for optimism or potential for working with risks and taking risks' (Morgan 2010). Risk is often considered in a negative way, as something tangible and physical that should be managed and avoided if at all possible. The voice of the person with dementia may be lost in a standardised risk assessment that is intended to safeguard them, inadvertently leading to further decline.

Risk assessments do not necessarily indicate the reason for the risk for the person with dementia. The risk may not arise from a deterioration in cognitive functioning, but rather from disabling barriers encountered by people with dementia. The use of bedrails is an example of this. They are intended to safeguard a person from falling. However, their use can increase the risk of harm

BOX 1

Case study: knowledge of the individual

Peter was alarmed one day when he was contacted at work by care services. They had visited his mother at their home to find her cutting up the dress she was wearing. They felt this bizarre behaviour required urgent (crisis) attention, until he reassured them that his mother had worked all of her life as a dressmaker and cutting fabric was something she enjoyed doing. She had a box of fabric beside her and only needed to have a piece of fabric passed to her so that she could continue to do something that was meaningful to her.

if the person is confused and attempts to climb over them; they also constitute a form of restraint (Mental Welfare Commission for Scotland 2013).

Risk assessment has an important role. However, the *Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry* (Francis 2013) emphasised the importance of ensuring that regulatory systems do not come before the needs of the person or their experience.

Approaches to managing risk

Our challenge as practitioners is to support people in their present and future. Sabat *et al* (2011) appealed to practitioners to prevent the person's past and future life from being overshadowed by their dementia: 'We should not let words rob people with dementia of their life story, their humanity, and a life yet to be lived'. Therefore, we should know people's life story, know them and their ambitions, and support them to realise these ambitions. We should think less about protecting someone and avoiding risks, and more about determining which risks it is reasonable, and important, to enable someone to take so that they may attain a sense of achievement and purpose in their lives.

Alaszewski *et al* (1998) identified three distinct roles for practitioners in risk management that vary according to whether risk is viewed as a hazard, as potentially empowering or as a dilemma. These roles are not exclusive, and the practitioner may use all of them simultaneously, including (Alaszewski *et al* 1998):

- ▶ When risk is viewed as a hazard, the practitioner acts as a hazard manager, identifying hazards and removing or minimising their potential to cause harm.
- ▶ When risk is viewed as potentially empowering, the practitioner acts as a risk facilitator, identifying and supporting activities which improve the person's quality of life.
- ▶ When risk is viewed as a dilemma, the practitioner acts as a dilemma negotiator, identifying and reconciling differing views and seeking a consensus between those involved, for example the person with dementia, family members and practitioners of varying disciplines.

Consider, for example, your role as a nurse in discharge planning:

- ▶ As a hazard manager, you may be concerned with non-adherence with medication.
- ▶ As a risk facilitator, you may be concerned with how someone may get out of their home and benefit from physical exercise and social engagement.

- ▶ As a dilemma negotiator, you may find yourself reassuring relatives who are requesting admission to a care home for their family member with dementia, rather than discharge home.

Poole *et al* (2014) identified that staff form a view about the mental capacity of a patient in hospital soon after admission and rarely revisit their view. In the context of multidisciplinary team decision making, it is essential that we consider how a practitioner might influence decisions about discharge destination and be a dilemma negotiator or risk facilitator rather than a hazard manager. Carson and Bain (2008) emphasised the importance of being prepared to take risks: 'Quite simply, risk taking is sometimes a duty. Not taking a risk can be bad professional practice. Often the real problem is that too few, not too many, risks are taken'.

Place and culture of care

Kitwood (1997) described general hospitals as 'traditional, safe environments' that are able to meet the basic needs and physical care of a person, yet continue to fail people with dementia. Kitwood's (1997) categories of need recognise important areas that contribute towards positive wellbeing in dementia, which include attachment, comfort, identity and inclusion. These categories of need are often compromised for people with dementia in hospital, with little opportunity for maintenance or enhancement.

Robinson *et al* (2007) emphasised the differences in priorities between practitioners caring for people with dementia who placed priority on safety over autonomy, and family and carers who placed emphasis on maintaining the person's autonomy. Gilmour *et al* (2003) reported that physical safety was the essential focus for health care, while the ability to 'maintain self-identity and key relationships' was of more importance to the person with dementia and their family.

The work culture in healthcare settings is influenced by the biomedical model with its focus on the individualisation of behaviour (Bond 1992). This can make it challenging to attempt to work differently and to consider what it means for a person with dementia to feel safe and secure in ways that extend beyond physical safety.

Considering risk from a biomedical model perspective can result in diagnostic overshadowing where presenting behaviours, such as shouting or pacing, are seen as a result of the disease process. A person-centred approach would view the person behind the diagnosis and consider other

possible causes of distressed behaviour, such as the environment (Clarke 2000).

Kitwood (1997) described the 'objectification' of people with dementia which may still be observed, for example through the use of language referring to people as a 'faller', 'feeder', 'wanderer' or demented. The term 'sitter' is still used to describe the deployment of additional staff to supervise patients on a hospital ward who, for example, are deemed to be at risk from falling if left alone. However, this role is often passive and intended as a means to control the physical risk, rather than an opportunity to participate in meaningful occupation and engagement with the person with dementia.

The use of technology, such as sensor pads for beds or chairs, to support safe movement in hospital, care homes and the person's home may be viewed as enabling for people with dementia, but may also be considered as a form of restraint and a deprivation of liberty (Mental Welfare Commission for Scotland 2013). For example, there is the danger that the use of audible bed alarms in hospital, although used with the best intentions, might constitute intimidation (Kitwood 1997), whereby the noise emitted from the alarm each time the person attempts to rise proves distressing for the person with dementia, and so they remain seated. This may affect the person with dementia's sense of self adversely, and may lead to continence problems if the person stops getting up to use the toilet.

Non-ambulatory status is a risk factor for inappropriate catheter use (Munasinghe *et al* 2001). Not being given the opportunity to undertake such basic activities as going to the toilet, leaving the ward or walking unaccompanied because others do not believe the person to be capable of managing the potential risk involved, may further deprive the person of their sense of identity and purpose. This is a breach of human rights that may lead to feelings of disempowerment and hopelessness (Bender and Cheston 1997). It may result in deskilling and deterioration in the person's physical and cognitive functioning, thus increasing their risk of harm.

Challenges and opportunities in risk management for person-centred care

In Western society, the view of dementia is often negative and dominated by constructs of loss, living death or carer burden. The public inquiry into Mid Staffordshire NHS Foundation Trust (Francis 2013) emphasised the negative societal attitudes towards older people that were felt to

have contributed to the episodes of lack of care at Stafford Hospital. Such negative attitudes influence the perceptions of staff in a hospital setting, who may already be working within a deficits model in which people with dementia are viewed as a homogenous group of people experiencing extensive loss of abilities. While it is important to acknowledge the challenges of caring for a person with dementia, the opportunity for discovery, giving, love and reciprocity should be considered (Smebye and Kirkevold 2013).

Bailey *et al* (2013) recognised that staff want to work in an increasingly person-centred way and place emphasis on promoting resilience. They observed that this is often not fully realised because of an organisational emphasis on keeping people free from harm, in which staff adopt a role as a hazard manager for fear of reprisal if an incident occurs. It can be challenging to achieve the appropriate balance between organisational requirements to manage risk in relation to physical safety and the right to self-determination for the person with dementia, their family or carer. Titterton (2005) argued that a risk-enabling approach enhances the person's wellbeing through meaningful choice and opportunities for self-determination. Talking to people to find out what and who matters to them and what they want to achieve can help to enhance a person's resilience and support their sense of personhood and self, which are important to promote wellbeing.

Families place more emphasis on autonomy than practitioners (Robinson *et al* 2012) because they have increased knowledge and understanding of the person's life story before they received the diagnosis of dementia and are able to make connections with current perceived risks and how this might relate to their previous experiences. Finding out more about the person with dementia can help inform practitioners about what is important to the person with dementia, including their needs, preferences, likes, dislikes and interests. This may be achieved using positive dialogue, the use of anticipatory care plans or simple tools such as *This is Me* (Alzheimer's Society and Royal College of Nursing 2011) or *Getting to Know Me* (Alzheimer Scotland and The Scottish Government 2013). These should help practitioners achieve a balance between autonomy and safety while acknowledging the person's strengths and assets.

It is, however, still necessary to reduce the physical risks associated with people with dementia. For example, moves around a hospital ward, within a hospital or inter-hospital transfer can exacerbate confusion and increase levels of distress. Unless practitioners know what the person is usually like, delirium superimposed on

dementia may be missed as a result of diagnostic overshadowing – the assumption that all behaviours can be attributed to the diagnosis of dementia. The symptoms of delirium, for example agitation, restlessness, distress, increased confusion or withdrawal, may be misdiagnosed as resulting from dementia rather than from a medical emergency. Delirium prolongs hospitalisation for people with dementia, is associated with functional decline and results in up to 25% of people with dementia and delirium dying within one month of discharge from hospital (Fick *et al* 2013).

Consider the case study in Box 2. It is important to understand that behaviour that may be deemed challenging by practitioners and others may result from the person with dementia communicating an unmet need or reacting to silent harm (Clarke *et al* 2011). Such understanding can prevent behaviours being perceived as risky but rather as a response to a person's reality or needs, so that staff can consider if there is anything that can be done to meet that need.

While it is not always possible to reach an agreement about risk between practitioners, the person with dementia and their family or carer, it is important to hear everybody's perspective of risk (Department of Health (DH) 2010). The *Charter of Rights for People with Dementia and their Carers in Scotland* (Alzheimer Scotland 2011) reflects standards around *The Universal Declaration of Human Rights* (United Nations 1948). This helped to inform *Standards of Care for Dementia in Scotland* (The Scottish Government 2011), which states the right for people with dementia to be regarded as unique and independent individuals. The Adults with Incapacity (Scotland) Act 2000 safeguards the rights of people deemed to lack capacity, detailing a set of core principles for interventions, including that they must benefit the person, involve minimal restriction on their freedom, take account of the person's past and present wishes, and encourage the use of their existing abilities and development of new skills.

Such policies and standards shape our perceptions and understanding of risk, as do the

cultures we work in and our personal narratives, values and life experiences. These, in turn, influence what we consider as acceptable or unacceptable levels of risk (Douglas and Wildavsky 1982) and shape the way we respond. Each person's journey is unique as a result of their different experiences. Therefore, it is difficult to work in a standardised format, and risk assessment and management should be personalised.

It is essential to understand the person's lived experience, to know what support they have and their important relationships, and to identify what keeps them well and the strengths they possess. An understanding of the person's lived experience informs care to avoid situations which might contribute to distressed behaviour and have the potential to increase risks.

Some of the main issues to address if we are to support quality of life by enabling risk taking, rather than avoiding risks, are to (Clarke *et al* 2011):

- ▶ Enable people to manage uncertainty rather than create certainty, to avoid unnecessary dependence and risk avoidance.
- ▶ Advocate effectively the views of the person with dementia, involving them in decisions about risk taking or risk avoiding.
- ▶ Ensure that the risk assessment includes psychosocial and emotional wellbeing as well as physical safety.
- ▶ Ensure that there is effective communication within and between services.

One useful tool for practitioners attempting to balance risk decisions has been developed by the DH (2010). In this tool, the likelihood of harm is assessed as low to high, along with the contribution of an action to quality of life as low to high. Those actions with a low likelihood of harm and a high contribution to quality of life should be continued. Those with a high likelihood of harm and a low contribution to quality of life should be ceased.

Many things will fall into a central area between these extremes, in which case the action should continue with new safeguards put in place or should be substituted for another related activity. Bryden (2005), as a person with dementia, asked that staff 'encourage us to be positive, hope for a new life in the slow lane, as we reach for the stars together'.

Conclusion

It is only through person-centred care that we can understand what is important to a person with dementia in their life and in the context of

BOX 2

Case study: considering the patient's view

Fred had removed all of his clothing and was standing looking out of the hospital ward window. His catheter bag was unsupported and unattached to his leg. The nurse noticed this and, without speaking, bent down behind him to secure the catheter bag. This startled Fred, who reacted by pushing away the person who was, in his mind, fumbling with his leg. Fred was thereafter regarded as an aggressive patient.

their family, social networks and community. This understanding enables us to maintain the wellbeing of the person by giving their lives purpose and meaning. Person-centred care means accepting and enabling risk to improve quality of life **NS**

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