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Abstract

Risk management for people with dementia has traditionally focussed on preventing physical harm. However, recent research has demonstrated that a focus on physical safety only can result in the social and psychological wellbeing of people being overlooked – the very things that person-centred care require us to attend to. This paper discusses some of the challenges for practitioners working with people with dementia in all care settings and encourages an approach which enables risk taking as a way of promoting person centred care.

Using Risk Management to Promote Person-Centred Dementia Care

Risk, harms and dementia

Risk is an accepted part of our everyday lives with almost everything we do involving some sort of risk, whether it is driving the car to work, crossing the road to meet up with friends or, for some, participating in activities such as climbing or mountain biking. This paper explores some of the issues concerned with how we understand risk in healthcare, and how we can approach risk assessment and management with people with dementia in a way that enhances person centred care. The paper encourages reflection on the situations that you might face in practice in all care settings.

In general health care settings, risk is considered in a largely negative way, as something that needs to be minimised if not completely eliminated (Health Education Authority, 1997). Risk has been around, although not necessarily recognised as a concept, for thousands of years but the word originates from the Italian word *risicare* which means to dare and was considered then to be more about choice rather than fate (Bernstein, 1996). Compared with the predominant thinking around risk in western society today as 'the possibility of incurring misfortune or loss' and 'to expose to danger or loss' (Collins, 1988), there has clearly been a shift towards framing risk as something to be avoided rather than embraced. That shift towards it being something to be avoided, coupled with the fear of litigation, act as motivations for many organisations to seek the management of risk through its avoidance rather than positive risk taking.

Re-positioning risk as a necessary part of quality of life is essential to person centred

dementia care, and something we are starting to see in recent policy guidance (e.g. Morgan

& Williamson 2014) and new social enterprises such as Dementia Adventure

(http://www.dementiaadventure.co.uk/). Kitwood (1997), in his seminal work on

dementia, highlighted the 'malignant psychology' that someone with dementia is likely to

experience and its very detrimental effect on their wellbeing. It is important to contrast a

situation in which someone with dementia experiences aspects of life that are important to

them being taken away (being stopped from cooking for example), with the risk of harms

that health and social care staff might often identify (the risk of falling or the risk of

becoming missing for example). The former have been termed as 'silent harms' (Clarke et

al. 2011) – they can be hard for us to notice (unlike if someone fell, for example) but which

very subtly take things away from someone.

Titterton (2005), too, argues that managing risk by attending only to physical safety can

lead to:

- Ignoring other needs
- Denying right to choice and self-determination
- Loss of a sense of self-esteem and respect
- A form of institutionalisation with loss of individuality, volition and increase in
  dependence
- At its worst, can lead to abuse of vulnerable people.

In day to day decision making situations, the dilemmas faced by many of the respondents to

a survey about risk management and dementia concerned how they seek to balance

independence and autonomy with exposure to potential harm (Clarke et al. 2009). Roger (2008) reports on a qualitative study, writing that: 'Their declines do not put an end to laughter, making meaning, and cherishing important relationships'. In considering the nursing care of people with dementia, we face the challenge then of placing at the centre of our decision making that person (who happens to have dementia) and not the dementia (which happens to be part of a person). One key way of thinking about this which we may find helpful is in moving from thinking about people being vulnerable (and so needing to manage their risks and harms) to understanding that it is a situation within which someone is vulnerable – that is, vulnerability is part of the context of a situation and not inherent in the individual. Thinking of it this way allows us to think of enabling risks, and positive risk taking, to enhance quality of life.

Thinking of risk assessment and management as a way to enhance quality of life opens up new ways in which we can support people with dementia. We are no longer constrained to managing them as inherently a person-at-risk, but can attend to their social and physical environment to provide a supportive environment.

One useful risk concept to consider is time-framing (Clarke & Heyman 1998) which helps explain why it is hard for health and social care staff to focus on the individual person. As healthcare staff, we are educated about the condition of dementia. We seek out, in our initial and ongoing assessments, evidence of where someone fits into the spectrum of dementia and in our future, or prognostic, outlook we see the path of dementia. For lay people (the person with dementia and their family for example), they have a knowledge base built from knowing of the individual, and they seek evidence of the continuity of that

individual – they are assessing today against past experience of that one individual, not assessing today against a future of many people with dementia. Peter, for example, was alarmed one day when contacted at work by care services who 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 dress maker and cutting fabric was something she enjoyed doing. Indeed, she had a box of fabric beside her and simply needed to have a piece passed to her so that she could continue to do something that was meaningful to her. Here, Peter draws on his knowledge of his mother's (biographical) background and offers a context in which her behaviour had a person-centred explanation – the only context the care staff knew of was the pathology of dementia and so they interpreted her behaviour in that context.

Risk Assessment

There is an important drive to improve the experience of healthcare for people by reducing harm, mortality rates, adverse events and improving patient safety, with bodies such as Healthcare Improvement Scotland established to oversee this. Not surprisingly, we see large health organisations such as hospitals working from a risk adverse basis within a tight regulatory framework, placing emphasis on the physical aspects of safety and attempting to predict and manage risk through checkbox assessments and matrices (see Heyman et al. 2010 for a thorough analysis). This is essential of course if we consider conditions such as sepsis and the need to identify the risk of developing it at the earliest opportunity. However by focusing on assessing physical risks and harm there is the

potential to increase, often unintentionally, other less tangible harms including emotional, psychological and spiritual harms that negatively impact the person with dementia's sense of well-being (Clarke et al. 2011).

Kemshall et al (1997) argue that the 'tick-box mentality' of completing risk assessment forms often takes precedent over professional judgement and tells us very little about the person behind the diagnosis. The format of risk assessments is 'often negative in focus with little room for optimism or potential for working alongside risks or indeed to take risks' (Morgan, 2010). Risk is seen in a negative light as something tangible and physical that needs to be managed and avoided if at all possible with the voice of the person with dementia lost amongst the standardised assessment intended to safeguard and therefore (albeit inadvertently) leading to further decline. Furthermore, what risk assessments from this perspective don't necessarily show you is the reason for the risk which for example, might not be because of deterioration in cognitive functioning but the disabling barriers faced by people with dementia. The use of bedrails is an example of this - although intended to safeguard a person from falling, their use can actually increase the risk of harm if the person is confused and attempts to climb over them, as well as constituting a form of restraint (Mental Welfare Commission, 2013). Whilst the assessment of risk does have an important role to play, in the report of the Mid Staffordshire Public Inquiry, Francis (2013) highlighted 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 - this is an approach addressed too by Sabat et al (2011) who call on us to not let someone's past and future life be 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". We need, therefore, to know of people's life story, to know them and their ambitions, and to support them to realize these ambitions. This means that we need to think not so much about protecting someone and avoiding risks, but getting to know what risks are reasonable (and important) to enable someone to take in order for them to achieve a sense of achievement and purpose in their lives.

Alaszewski et al (1998) identified three distinct roles that practitioners have in risk management, which vary according to whether risk is viewed as a hazard, as potentially empowering or as a dilemma. These are not exclusive roles, and you may feel that you adopt all of these views at times.

- When risk is viewed as a hazard, the practitioner plays the part of a hazard manager, identifying hazards and removing or minimising their threat to cause harm.
- When risk is viewed as potentially empowering, the practitioner plays the part of a risk facilitator, identifying and supporting activities which add to the quality of life of someone.
- When risk is viewed as a dilemma, the practitioner plays the part of a dilemma negotiator, identifying and reconciling differing views and seeking a consensus

between say the person with dementia, family members and practitioners of varying disciplines.

Consider, for example, what role a nurse might play in discharge planning:

- As a hazard manager, you may be concerned with compliance with medication.
- As a risk facilitator, you may be concerned with how someone will 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 rather than discharge home.

Poole et al (2014) identified that staff form a view about the mental capacity of someone in hospital soon after admission and rarely revisit their view – if so, in the context of multidisciplinary team decision making, consider how a nurse might influence decisions about discharge destination and be a dilemma facilitator or risk facilitator rather than a hazard manager.

Carson and Bain (2008) make the point about the importance of being prepared to take risks very emphatically: '*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 Cultures of Care

Kitwood (1997) described general hospitals as 'traditional, safe environments' which are able to meet the basic needs and physical care of a person but yet continue to fail people with dementia. Kitwood's categories of need recognise key areas that contribute towards positive wellbeing in dementia which include attachment, comfort, identity and inclusion - if we consider the experience of people with dementia in hospital, we can see that these areas are frequently compromised with little opportunity for maintenance or enhancement. A study by Robinson et al (2007) highlighted the differences in priorities between professionals caring for people with dementia who placed priority on 'safety' over autonomy as opposed to family and carers who placed more emphasis on maintaining the person's autonomy. Gilmour et al (2003) report that whilst physical safety remains the key focus for healthcare, the ability to 'maintain self-identity and key relationships' is 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) and this can make it challenging to attempt to work differently and to truly consider what it means for a person with dementia to feel safe and secure in a way that reaches beyond the realms of physical safety. For example, considering risk from a biomedical model perspective, can result in diagnostic overshadowing with presenting behaviours, such as shouting or pacing, seen as due to decline in the disease process rather than seeing the person behind the diagnosis and other possible causes of distressed behaviour such as the environment (Clarke, 2000). Kitwood (1997) described the 'objectification' of people with dementia which is still seen, for

example, through the use of language referring to people as a faller, feeder, wanderer or demented. The term 'sitter' is still at times used to describe the deployment of additional staff to closely supervise patients on a hospital ward deemed to be at risk, for example, from falling if left alone - but as the word suggests, the role is often of a passive nature and used more as a means of attempting to control the physical risk rather considering it as 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 own home can be seen to be enabling for people with dementia but can also be considered as a form of restraint and a deprivation of liberty (Mental Welfare Commission, 2013). For example, there is the danger that the use of audible bed alarms in hospital, although used with the best intention, might constitute intimidation (Kitwood, 1997) as the noise emitted from the alarm each time the person attempts to rise might prove too distressing for the person with dementia so they stay seated. Not only could this adversely impact on the person with dementia's sense of self but there is the chance that this might also lead to continence problems if the person stops getting up to use the toilet, with non ambulatory status 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 can further deprive the person of their sense of identity and purpose. This breach of human rights can lead to feelings of disempowerment and hopelessness (Bender and Chester,

1997), and becomes a self-fulfilling prophecy resulting in deskilling and deterioration in the person's physical and cognitive functioning.

The Challenge and Opportunity of Risk Management for Person Centred Care

The view of dementia in western society is often negative and dominated by constructs of loss, living death or carer burden. The Mid-Staffordshire report (Francis, 2013) highlighted the negative societal attitudes towards older people which were felt to have contributed to the appalling episodes of care in Stafford hospital. And these negative attitudes in turn influence the perceptions of staff in a hospital setting who are already working within a deficits model of viewing people with dementia as a homogenous group of people experiencing extensive loss of abilities. Whilst it is important to acknowledge the challenges of caring for a person with dementia, it is also important to consider the opportunity for discovery, giving, love and reciprocity (Smebye and Kirkevoid 2013).

Bailey et al (2013) recognise that staff want to work in a more person-centred way and place more emphasis on promoting resilience, however the emphasis on keeping people free from harm and adopting a role as a hazard manager for fear of reprisal if an incident occurs means that this is often not fully realised. Challenges remain on how to overcome the conflict that can occur between the organisational requirements to manage risk in relation to physical safety and to support the right to self-determination for the person with dementia, their family or carer. Titterton (2005) argues that by adopting a risk-enabling approach, well-being is enhanced with 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 key to promoting wellbeing.

If we consider the study by Robinson et al (2012), the reason why families place more emphasis on autonomy is that they have a deeper knowledge and understanding of the person's life story prior to receiving 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 through positive dialogue, the use of anticipatory care plans or simple tools such as 'This is Me', developed by Alzheimer's Society and the Royal College of Nursing (RCN) (Alzheimer's Society & RCN, 2011) or the 'Getting to Know Me' document (Alzheimer Scotland and Scottish Government, 2013) can help inform staff about what is important to the person with dementia including their needs, preferences, likes, dislikes and interests. This will hopefully help staff gain a better balance between autonomy and safety whilst acknowledging the strengths and assets that the person possesses.

There is, though, still the need to reduce the physical risks associated with people with dementia. For example, the number of moves around a hospital ward, hospital or inter-hospital transfer can exacerbate confusion and increase levels of distress - without knowing what someone is 'normally' like, delirium superimposed on dementia can be missed due to diagnostic overshadowing (the assumption that all behaviours can be attributed to the diagnosis of dementia). Misdiagnosing symptoms of delirium such as agitation, restlessness, distress, increased confusion or withdrawal as due to the dementia

when in fact there is a medical emergency occurring will mean that (if not treated) up to 25% of this group will die within one month of discharge from hospital (Fisk et al, 2013).

There is also the need to understand that behaviour that could be deemed as challenging to staff and others might in fact be the person with dementia communicating an unmet need or a reaction to silent harm (Clarke et al. 2011). By understanding this, we can prevent it being perceived as risky behaviour but rather as a response to their reality at that moment and for staff to consider if there is anything that can be done to meet that need. For example, Fred had removed all of his clothing and was standing looking out of the hospital ward window, his catheter bag unsupported and unattached to his leg – the nurse noticed this and (without speaking) bent down behind him to secure the catheter bag, startling 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. Whilst it is not always possible to reach an agreement about risk between the ward staff, person with dementia and their family or carer, it is important to hear everybody's perspective of risk (Department of Health, 2010).

In Scotland, the 'Charter of Rights for people with dementia and their carers' (Alzheimer Scotland, 2011) reflects the standards around the Human Rights Act set by the United Nations (1948). This has helped to inform the 'Standards of Care for Dementia in Scotland' (Scottish Government, 2011) in which it states the right for people with dementia to be regarded as unique and independent individuals. There is further support to safeguard the rights of people deemed to lack capacity under the Adults with Incapacity (Scotland) Act (2000) which details a set of core principles for interventions - that they must benefit the

person, involve minimum restriction on their freedom, take account of the person's past and present wishes and encourage the use of existing abilities and develop new skills (Scottish Executive, 2000)**.**

Policies and standards such as these shape our perceptions and understanding of risk, as do the cultures we work in, our own personal narratives, values and life experiences which in turn influence what we then consider being unacceptable or acceptable levels of risk (Douglas and Wildavsky, 1982) and shape the way we respond. Because everybody's journey is unique as a result of their different experiences, it is difficult to work within a standardised format and the assessment and management of risk needs to be personalised. It is essential to understand the person's lived experience, to know what supports they have and their key relationships, and to identify what keeps them well and the strengths they possess. Having a deeper understanding of the persons' lived experience will inform care to avoid situations which might contribute to distressed behaviour (and the subsequent potential to increase risks).

So what are some of the key issues to address if we are to support quality of life by enabling risk taking rather than trying to avoid risks (Clarke et al 2011):

- Enable people to manage uncertainty rather than create certainty - to avoid unnecessary dependence and risk avoidance

- Effective advocacy of the views of the person with dementia – involve them in decisions about risk taking or risk avoiding

- Ensure that assessment includes psycho-social and emotional wellbeing as well as physical safety

- Ensure that there is good communication within and between services.

One very useful tool for staff to use in balancing risk decisions has been developed by the Department of Health (2010). In this tool, the likelihood of harm is assessed (low – high) as is the contribution of an action to quality of life (low – high). Those actions with a low likelihood of harm and a high contribution to quality of life should be continued with. Those with a high likelihood of harm and a low contribution to quality of life should be ceased. Many other things will fall into a central area between these extremes, in which case an action should continue with some safeguards in place, or should be substituted for another related activity.

Conclusion

Person centred care means accepting and enabling risk to improve quality of life. It is only through being person centred that we can understand what is important to the individual in their life and in the context of their family, social networks and community – and knowing this will enable us to work to maintain the wellbeing of someone through conferring purpose and meaning to their lives. We will give the last word to Bryden (2005) who, as a person with dementia, asks that we: 'encourage us to be positive, hope for a new life in the slow lane, as we reach for the stars together'.

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