

Risk communication in dementia care practice

Why is risk communication important?

Living with dementia can mean that some individuals are more likely to experience risks in daily life. These may include risks to physical safety or to emotional wellbeing. Risks experienced will be unique for each individual depending on factors including the progression of their dementia, co-morbidities, supports in place and their environment.

Health and social care practice in dementia care often involves making judgments involving risks or providing advice to people with dementia and families around risks.

Risk communication in dementia care involves *sharing information* and *sharing ideas and preferences* about risks between people with dementia, family carers and health & social care practitioners.

Risk communication should be central to shared decision making processes. In order to make informed decisions about their health and social care, people with dementia and their families need to be aware of the potential benefits and harms in the different options available to them.

This document summarises key findings from a research project at Ulster University on *Risk Communication in Dementia Care*. Practical tips based on these findings are included. Information on research methodology is given later in this summary.

What does risk mean to people with dementia, family carers and health & social care practitioners?

Risk means different things to different people. Risks that are acceptable to one person, might not be to another. Acceptability can also change over time. Developing shared understandings of risk between people with dementia, families and practitioners is important to ensure that communications are meaningful and person centred.

What did people living with dementia think about risks?

"It's really important that you can be independent but safe."

"If you don't take a chance you get nowhere!"

- Risk was associated with danger and vulnerability for some individuals.
- Risk sometimes held emotional connotations for example feelings of fear or worry.
- For some individuals, risk made them think about being more careful.
- Others said they did not usually think about risks in their daily life.

- Risk was often thought of as a situation or action having an undesired consequence. Sometimes these consequences had actually happened, sometimes they were things that individuals worried would happen.
- Understandings of risk were informed by life history (including former occupation), psychological processes (personality and emotions) and media, and are continually shaped by experiences and situations encountered.
- The risks that people with dementia talked about the most were going out alone, driving, using the oven, looking after grandchildren alone and hobbies including gardening, socialising or woodwork.
- There was ample evidence of participants with dementia expressing their concerns and wishes around risks with practitioners and family members.
- Both active and passive models of decision making were evident.
- Decision making (involving risks) for people with dementia was often strongly connected with emotions.

What did family carers think about risks?

“Risk is not to be avoided. It is to be managed.”

- Family carers often associated risk with danger, harm, accidents and being vulnerable.
- Risks were often a source of stress and worry for families.
- Family carers thought of risk as a (negative) consequence rather than as the likelihood.
- Some family members agreed that taking risks could also lead to worthwhile outcomes that outweighed the risk.
- The risks that family carers were most concerned about were driving, falls, financial risks, getting lost and accidents from using electrical appliances.
- For family carers, risk communication often centred on making the person with dementia aware of risks.

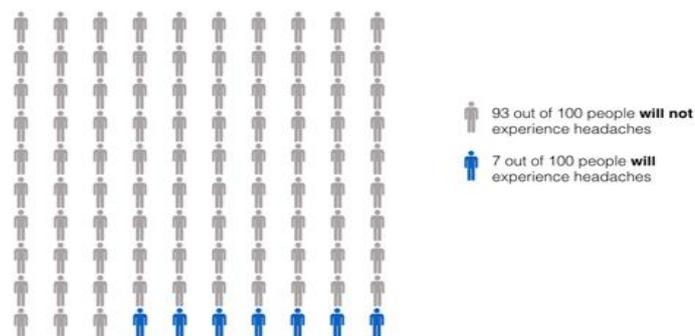
What did health & social care practitioners think about risks?

“Our role is not to come in and dictate to people what’s acceptable or what’s not. It’s about supporting them in what they want to do and keeping them safe”

- Practitioners saw taking risks as having potential positive and negative outcomes.
- Participants talked about supporting and enabling individuals to take positive risks.
- Practitioners generally did not refer to the likelihood aspect of risk i.e. how often certain risk outcomes were actually occurring.
- Concepts were influenced by the risk management culture for example risk assessment tools and professional terms such as ‘proportionality’ and ‘liberty.’ Wider discourses on positive risk taking also influenced concepts.
- The risks that concerned practitioners the most included people with dementia being mistreated by others, falling, depression, medications mismanagement and fire.

Communicating risk

- Numeracy is relevant to risk communication in dementia care practice. 86% of health and social care practitioners who participated in our survey were using numbers in their roles. These included assessment scores (for example the Mini Mental State Exam), statistics from team databases and information relating to frequency of side effects of medicines.
- However, practitioners reported that they were typically not using number expressions (such as percentages or frequencies) in their communications with clients and other staff.
- Reasons provided for not using numeric expressions included clients not asking for numbers, staff not feeling comfortable using numbers or not seeing such communications as appropriate.
- Practitioners showed a preference for verbal expressions of likelihood of side effects of medications for example 'low' or 'most common.' Such verbal expressions by their very nature are less precise and more ambiguous than using numbers.
- Professionals demonstrated a high level of variance in the verbal expressions they selected as corresponding to specified numeric values. For example 39% of survey respondents described 21 out of 1000 as 'rare' while 45% described this value as 'uncommon.'
- There was also a high level of variance in the numeric values (estimated out of 1000) assigned to the terms 'common' and 'rare'. This high level of variability may lead to a lack of consistency in communications of risk likelihoods in practice.
- Practitioners were markedly overestimating how frequently low probability risks with severe outcomes were actually occurring, compared to recorded data. These risks included having a car accident, causing a fire, being hospitalised after a fall or going missing. This may mean that professionals are being more risk averse than they need to be.
- 80% of practitioners expressed a preference for using visual formats for communicating side effects of medicines to complement verbal statements (icon arrays, 51%; bar charts 29%) rather than a verbal frequency statement alone. Below is an example of an 'icon array' showing how many people out of 100 who take a medication will experience headaches.



- Challenges for communicating risks in practice (ranked in descending order of concern) included: conflicting ideas on client's best interests; person with dementia lacking insight into the risk; unrealistic expectations of services; risk of damage to professional/client relationship; lack of data on likelihoods; and fear of complaint.

Practical recommendations for practitioners

- Be aware of the individual's personal history and how this may make them think about risks – for example their job history, hobbies, personality and experiences.
"We might go into a house and think 'gosh that's wild risky' [but] they might have been doing it all of their life" (professional)
- People with dementia should be supported wherever possible to think about risks for themselves rather than being told what to do. This could involve sensitively bringing the risk to their attention e.g. 'how are you managing with...' or 'the traffic was very bad today, do you also find that?'
"I don't like to be treated like a child. I am quite happy to be independent, but sensible" (person with a dementia)
"Instead of telling the person the risk, it's trying to get them to think about and identify the risks themselves" (professional)
- Choose the right time to talk about the risk with the person with dementia. Some individuals find that there are certain times of the day when they feel more confident making choices.
- Give the person with dementia time to think before making a decision.
"You see I am trying to make a decision but there's millions of things going through my head too" (person with a dementia)
- If you are worried about a person with dementia, sensitively talk through the reasons why you think it may not be safe for that person to continue with a particular activity.
"If it makes sense to me then that's fine" (person with a dementia)
- Focus on solutions rather than problems e.g. *'have you thought about trying...'*
- Use positive language in communications for example words such as *'safety'* or *'independence.'*
- Write down any important points for the individual as a visual reminder of the conversation.
- Practical information for family carers should include advice on dealing with risk in everyday life. This could include general guidance in the form of group information sessions, written materials or personalised advice.
- Translate important professional concepts such as *positive risk taking* and *proportionality* into everyday language for families and people with dementia.
- Consider using visual aids to communicate risks to people with dementia and families.
- Assemble data on frequency of risk outcomes as a reference point for staff. Overestimations of risk might be expected to lead to risk averse practice. Communicating more accurate likelihoods to service users may encourage people with dementia and families to worry less about risks that are actually very unlikely to occur.

Research methodology

What we were interested in

- How risk is conceptualised by people with dementia, family carers and health and social care practitioners.
- How these groups communicate about risks with each other.
- How this communication can be improved to support people with dementia and families to make decisions about their daily life and care.

What the study involved

- A systematic narrative literature review of 'risk concepts' and 'risk communication' in dementia.
- Interviews with 17 people with dementia who had recently made a decision where they had to think about risks, for example whether to continue driving, move to supported living accommodation or use assistive technology.
- Five focus groups involving 22 family carers.
- Five focus groups involving 35 health and social care practitioners working in dementia care.
- Web-administered survey with 70 health and social care practitioners (plus 55 partial responses).
Health and Social Care practitioners included nurses, social workers, doctors, occupational therapists, speech & language therapists, psychologists and support staff.

For more information on this study and for links to published journal articles, please go to <http://www.socsci.ulster.ac.uk/irss/risk.html>

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Useful reading

Risk Communication in Dementia Study website. <http://www.socsci.ulster.ac.uk/irss/risk.html>

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