Risk and dementia

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Abstract

People with dementia and their family carers may be subject to a number of different risks; these risks may overlap with, and impact on one another. Due to changes in capacity that come with dementia, people with the diagnosis may be overly cautious about decisions made relating to risk made on their behalf, and this may have a negative impact on their wellbeing and quality of life. This article aims to educate community nurses on the risks they need to be aware of when working with families affected by dementia, and presents a risk enablement framework as a way of assessing and managing risk in a person-centred way.

Keywords: Capacity • community nursing • dementia • family carers • risk • safeguarding

Risk is an inherent part of our day-to-day lives, and we will make decisions about taking, or not taking certain risks almost without being aware of it (e.g. taking a car journey or crossing a road). We take for granted our ability to assess and negotiate these daily risks, allowing us to live our lives with a balance of taking risks, maintaining our safety, and our quality of life. However, when someone is diagnosed with dementia, there is often an immediate question placed over their capacity to make decisions for themselves, including those about taking risks (Dickins et al, 2018). As such, people with dementia may find themselves subject to overly cautious decisions made on their behalf, which can have a negative impact on their quality of life.

Table 1. Domains of risk in dementia

Domains of risks	Examples
Physical	Falls, dehydration, malnutrition, delirium, skin integrity
Social	Home safety risks, driving, getting lost
Mental health	Violence/aggression, suicide/self-harm, substance misuse
Safeguarding	Domestic, psychological, physical, sexual or financial abuse

Note: Adapted from the Department of Health (2010)

Dementia is encountered frequently in community nursing settings, with an estimated 994 000 people in the UK currently living with this condition (Wittenberg et al, 2019). Dementia is a set of symptoms caused by progressive neurological changes in the brain, including declining cognitive function, problems with memory and recall, language and personality, as well as social changes (Sandilyan and Dening, 2019). There are many causes of dementia, the most common being Alzheimer's disease, but with vascular dementia, mixed dementia (usually Alzheimer's disease and vascular dementia), dementia with Lewy bodies and frontotemporal dementia – all being seen frequently as well (Cullum and Taye, 2020). Dementia has an impact, not just on the person diagnosed with the condition, but also on the wider family unit. There are currently around 700 000 family carers looking after someone with dementia (Lewis et al, 2014), and a growing understanding of the importance of working within a family-centred model of care for the healthcare professional (HCP) to effectively support this group of people well (Dening and Hibberd, 2016).

People with dementia and their family carers can be subject to several different risks including physical risks, mental health risks, social risks and safeguarding risks (Clarke and Mantle, 2016) (*Table 1*). It is also important to be aware of possible child protection risks, and this may be particularly important in young-onset dementia, or multi-generational households, where children and young people live alongside the person with dementia or may be family carers themselves.

It is also important to have an awareness of how each of these risks might overlap with the others (*Figure 1*); for example, a person who is at risk of skin breakdown and is having to be turned in bed regularly, might also then be at risk of experiencing agitation or aggression because of their lack of understanding of the need for this regime to protect their skin. Likewise, a risk experienced by the person with dementia, might also impact on the family carer and vice versa. For example, where the person with dementia is experiencing periods of aggression directed towards the carer, the carer may then be placed at risk of physical harm, or of experiencing mental health risks, like thoughts of self-harm or suicide.

Risk in practice can cause anxiety for nurses, with concerns about having difficult conversations about risk, missing risks, or being too risk averse. While community nurses are in a unique position of being able to identify a range of risks during their contact with families affected by dementia, it is important to remember that identifying

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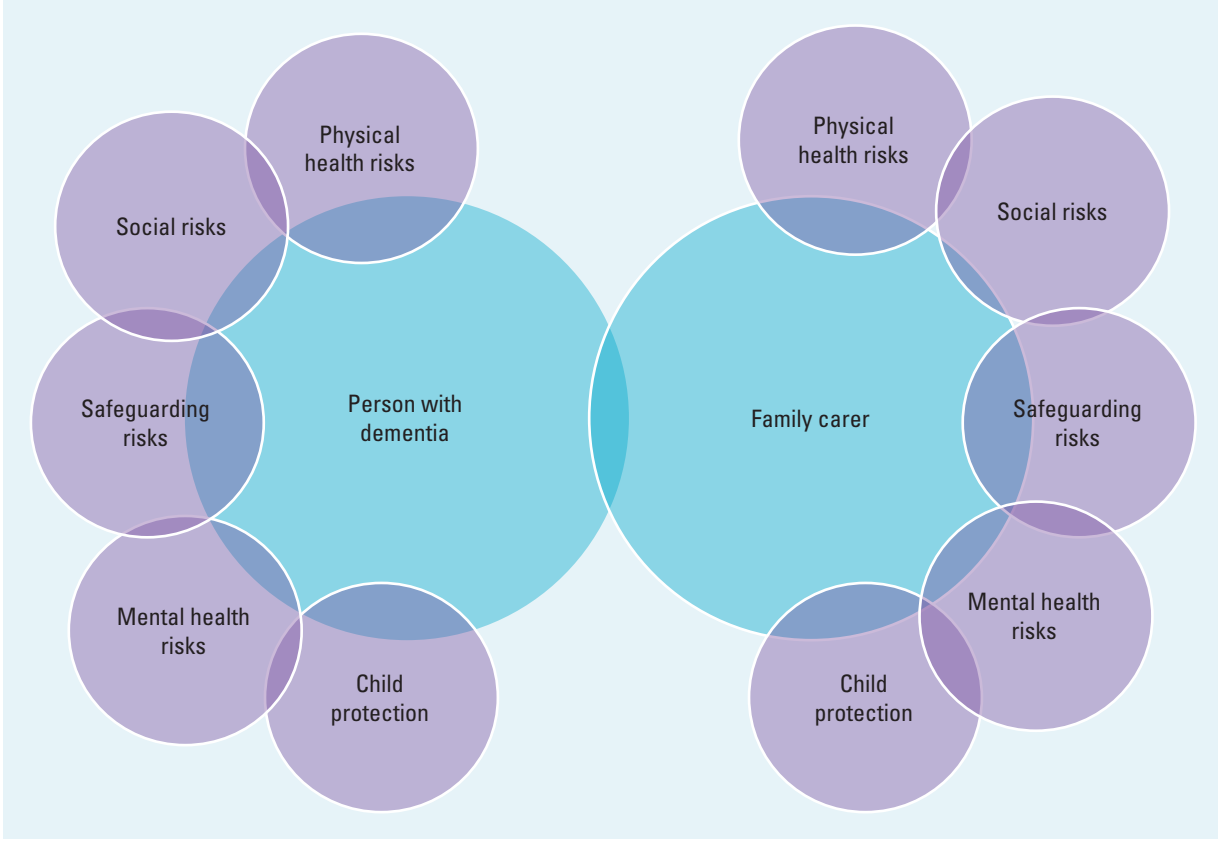

Figure 1 shows how different risks overlap with others

a risk does not make the HCP responsible for that risk. While some risks (e.g. physical health risks) may be directly managed by community nurses, many others (e.g. risks of suicide and self-harm) will need referral to other specialist services. It is important to always practice within one's own skills and expertise and be aware of how to access other services, as needed.

The concept of risk assessment and management in practice will be explored further, through the lens of two case studies.

Risk enablement

Box 1 looks at the case of Henry, and his wife Gail. In Henry's situation, it is clearly demonstrated that by minimising a risk in one area (in this case, it is his risk of falling when walking outside alone), it is possible to create new risks (such as risk of depression and agitation/aggression for Henry). Risk enablement is an approach rooted in person-centred care (Nazarko, 2016), which aims to balance the need for safety with the person's autonomy and quality of life. Moving away from the idea of risks as something to be avoided, it recognises the rights of people with dementia to be supported to make choices, to engage in activities that are meaningful for them, and to maintain independence as far as is possible.

The 'Nothing ventured, nothing gained' (Department of Health, 2010) risk guidance gives a good overview of this approach, which is sometimes also referred to as 'positive risk taking' (Mapes, 2017). Key to this approach is having an understanding of the person, not just in terms of their medical history and the impact of their dementia, but also their interests, experiences, and what is important to them. This may seem like a potentially time-consuming approach, but as seen in the *Box 1,* in the course of the dressing change the nurse was able to elicit a great deal of information about how both Henry and Gail were feeling about the new risk of Henry falling when he was outside. Therefore, gaining this important information about a person does not have to constitute an intervention in and of itself, nor does it have to be carried out by dementia specialists. Rather, it can be seen as an approach to care, and something that can be woven into the everyday interactions that community nurses have with the people in their care.

Once a risk has been identified, the next part of the process would be to assess the impact of the risk. A 'heat map' approach is suggested (Department of Health, 2010),

Box 1. Case study one: Henry and Gail

You are visiting Henry, who has a diagnosis of vascular dementia, to support with wound management following a fall he experienced when walking outside on his own a few days ago. Henry lives with his wife Gail. While you are changing Henry's dressing, Gail starts to tell you that since the fall outside, she has started limiting Henry's walks, and is now discouraging him from going out alone, preferring him to wait for times when she can accompany him. However, she has also noticed that Heny has started to become more withdrawn, and there has been one occasion where he has become very angry and shouted at her when she tried to stop him going for a walk alone. Henry is able to express that while he doesn't remember the particular incident where he became angry, that he is finding it hard not being able to go out alone, and he feels he has lost his independence.

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which supports the balancing of the impact of taking the risk, with the impact it can have on a person's quality of life and wellbeing (*Figure 2*).

When considering the risks for Henry going out alone using the heatmap (*Figure 1*), the HCP might assess the potential risk as medium. The records show that he has fallen in the past while out walking; however, he was able to get himself home and seek appropriate help with support from Gail. The HCP might also assess the contribution that walking has on his quality of life is also high – as Henry is feeling very low as a result of his lost independence and his inability to go out alone. The key principle of risk enablement is to identify and manage risks, without avoiding them altogether. This can be challenging when a family carer, understandably, wants to keep the person they care for as safe as possible. Therefore, part of this approach may also involve support and education for the carer. In this case, the community nurse might use the conversation between Henry and Gail to help Gail understand the impact of keeping Henry in the house, and other risks this is potentially creating. A collaborative plan could then be agreed upon, which in this case might involve referral to a falls team or occupational therapy team, to suggest approaches and aids that might reduce the risk of Henry falling while he is out. Additionally, the use of assistive technology, such as a GPS tracker, might help Gail feel happier about Henry going out alone.

Unsurprisingly, people with dementia are at a higher risk of experiencing abuse than the older adult population in general (Fang and Yan, 2018). Therefore, it is imperative that anyone working with people with dementia is aware of the potential risk for abuse, and understands what forms abuse might take, how to recognise abuse and what to do when abuse is suspected. Types of abuse as defined by the Care Act 2014 include:

- Physical abuse
- Domestic violence or abuse
- Sexual abuse
- Psychological or emotional abuse
- Financial or material abuse.

There are many different signs and indicators that someone may be at risk of, or experiencing abuse, including a sudden change in behaviour, loss of appetite, low mood, unexplained injuries or missing personal items.

In the case of Peter (*Box 2*), the community nurse rightly identified that he was experiencing financial abuse, and that this is at risk of continuing if appropriate action is not taken. When abuse is suspected or identified, you should always follow your local safeguarding policies and procedures. In most cases this will involve reporting your concerns to the local safeguarding team, usually based within the local authority, who will investigate the concerns and take appropriate action to keep the person safe.

As well as the person with dementia being at risk of abuse, a family carer may also be vulnerable. It is important to keep in mind that the carer may be subject to abuse from the person with dementia they are caring for, particularly where there are distressed behaviours present, such as agitation and aggression. Being alert to the signs of abuse and making time and space for open and honest communication with both the person with dementia and their carer during interventions are all important ways of making sure risks are identified and acted upon.

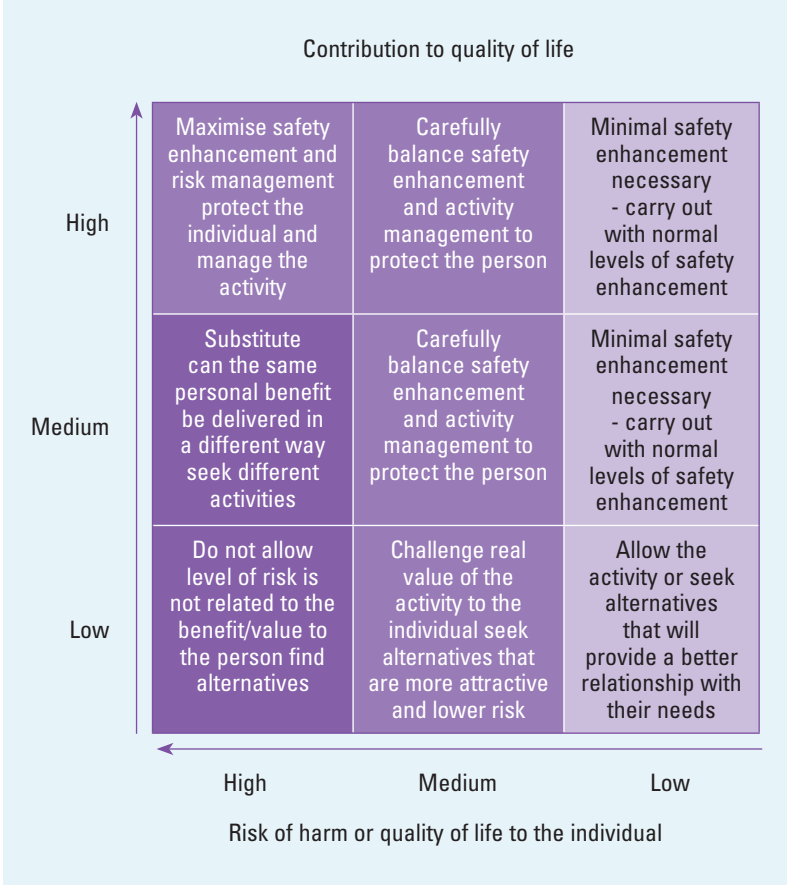

Figure 2. The 'heat map' approach shows how to balance the impact of taking the risk, with the impact the risk can have on a person's wellbeing and quality of life

Conclusion

It is important for community nurses, as well as nurses in all settings, to be risk-aware when it comes to working with people with dementia and their family carers. The potential risks that people with dementia and their families may be subject to are wide ranging and may impact on one another. However, as this article has shown, a 'safety first' approach also comes with potential risks to wellbeing and may negatively impact on quality of life for people with dementia

Box 2. Case study two: Peter

You are visiting Peter who has a diagnosis of Alzheimer's disease and who lives alone. Peter has diabetes and so your team see him regularly to administer his insulin injections. You notice that Peter seems less chatty than normal, and when asking him what is wrong, he discloses that a new friend he has made at the local community centre has been taking his money, leaving him with little to buy his food.

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Key points

- People with dementia and their family carers may be subject to multiple different risks, and risks in one area may overlap with, and influence, risks in another area
- Due to the progressive nature of dementia, people with the diagnosis may find their ability to make decisions for themselves questioned, leading to overly cautious decisions about risk being made on their behalf, with impacts on quality of life and wellbeing
- Risk enablement is an approach rooted in person-centred care that supports nurses to balance the need for safety, with the wellbeing and quality of life of the person with dementia.

CPD reflective questions

- Consider some of the daily risks that you take in your own day-to-day life – how do these contribute to your quality of life and how might you feel if the decision to take these risks was taken away from you?
- Think of a case from your practice where you encountered a person with dementia who was at risk in some way – use the heat map in *Figure 2* to map the level of risk against the contribution to quality of life
- Are you aware of your own local safeguarding processes and policy? If not take some time to familiarise yourself with these.

and their families. A risk enablement approach allows for both safety and quality of life to be considered in balance when managing risk. It is also vital that all community nurses are aware of the potential risk of abuse for both people with dementia and their family carers, the signs of abuse and local safeguarding processes. **BJCN**

Declaration of interest: *None*

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