

Steve Iliffe and Jill Manthorpe

Risk and danger are pervasive in dementia syndrome, from its cause through its course, to its care. When seen from a medical perspective, many people with dementia are the outcomes of risky behaviour, their neurodegeneration being the consequence of high alcohol consumption, obesity or smoking and other potentially modifiable ‘lifestyle’ behaviours.

The diagnostic label of dementia carries risks with it, one being that it can turn someone who is muddled and forgetful into the bearer of a stigmatised disease, propelling them onto an escalator to disability [1] or infantilism. The risk for the person with dementia is that they become ‘uncivil’, embarrassing and visibly lacking in self-control [2]. This risk appears along a spectrum from words lost and sentences not completed through messy eating to incontinence. Dementia is a condition well suited to an era of uncertainty and unease, in which risks clamour for attention and possible dangers crowd in from all sides. In this ‘risk society’, everyone is ‘subject to political rules of recognition, compensation and avoidance’ [3]. These political rules are made explicit in the National Dementia Strategy [4] and the Prime Minister’s Challenge for Dementia [5].

Behavioural and psychological symptoms such as aggression, agitation, ‘wandering’ and disinhibition, which typify dementia, create additional risks for the person with dementia and those around them by causing distress, misunderstanding and inappropriate reactions. These symptoms occur in 40 % of those people who

S. Iliffe, MBBS, FRCGP (✉)
Research Department of Primary Care and Population Health, University College London,
London, UK
e-mail: s.iliffe@ucl.ac.uk

J. Manthorpe, MA
Social Care Workforce Research Unit, Kings College London, London, UK
e-mail: jill.manthorpe@kcl.ac.uk

have ‘mild cognitive impairment’ and in 60 % of those in the early stage of dementia and often become more frequent and troublesome with advancing dementia. Carers spend much of their time supervising and controlling the care environment [6], and carers’ health may be at risk of harm from the stress of caring [7].

Understanding the risks associated with dementia matters to the care assistant in a nursing home as much to the community nurse who visits the home. They matter too to the community-based physiotherapist providing rehabilitation, to the practice nurse managing long-term conditions or to the social worker arranging for a ‘suitable person’ (generally a relative) to manage the social care direct payment and support plan.

This chapter explores what is meant by risk for people with dementia, describes which ‘risks’ cause most concern and offers some ways of understanding risk for people with dementia and their carers. It proposes three types of response to risk: a ‘safety-first’ stance; seeing benefits in risk; and adopting a right-based approach to risk taking, emphasising ‘risk enablement’ and ‘positive risk taking’. In practice cautious approaches to risk predominate, with risk seen as a danger more than liberation. ‘Managing risk’ is now as important as ‘meeting needs’, at least in social care [8].

26.1 Dementia and the (Dis)embodiment of Risk

The possibility that dementia could be prevented focusses attention on the ‘risk of’ developing dementia, with the cause of dementia being attributed to multiple ‘risk factors’. The ‘risk factor’ approach reduces change to decontextualised and disembodied behaviours and exposures, with potential for blaming the individual’s present condition on their past lifestyle choices [9] or sometimes their genes. The alternative is the embodiment of risk, which finds clues about current health in the dynamic social, material and ecological context into which we are born, develop, interact and endeavour to live meaningful lives [10]. The wide range of possible risk factors – from gum disease to sleep disturbance in midlife, not forgetting all cardiovascular risk factors and head injuries – suggests that the causes of dementia are multiple and as much environmental as behavioural. The embodiment view of dementia risks fits the evidence better, but it is harder to grasp, measure and manipulate, which may be why the epidemiological ‘risk factor’ view is more popular, at least in medicine. This epidemiological view only allows for safety-first approaches – we should not smoke, drink too much, eat too much and exercise too little, or we may get dementia. And we should keep our cholesterol levels and blood pressure low with medication, too.

26.2 The Hazards of Diagnosing Dementia

Incorrect categorisation of other forms of behaviour or cognitive change as dementia creates the potential for under-treatment of treatable conditions like depression and the misdirection of individuals and families to inappropriate services. The

increased referral of individuals to specialist services or memory clinics may heighten patient and family anxiety during investigation and even reduce availability of such services by extending waiting times. A ‘false-positive’ diagnosis may jeopardise patient and family trust in practitioner judgements.

The desire to communicate honestly and directly with a patient may be at variance with an equally strong desire to accept a family’s reluctance to disclose the diagnosis [11]. This problem exists for specialists as well as generalists, with 60 % of psychiatrists and geriatricians in one UK study over a decade ago regularly not telling patients their diagnosis because of concerns about the patient’s insight or about possible detrimental effects [12]. In the United Kingdom (UK) with the pressure for early or timely diagnosis, this situation is likely to have changed [13]. However, practitioners have every reason to be anxious about risks and hazards in diagnosis, given the intense debate about the balance of benefits and harms of an early diagnosis in dementia and the suggestion even of a ‘curse of diagnosis’ [14]. Alzheimer’s Disease International has pointed out that there is almost no research conducted into the effect of the timing of dementia diagnosis upon subsequent disease course and outcomes for the person with dementia and their carers [15].

Being at risk because of having dementia has consequences for everyday life – such as not being able to obtain travel insurance easily or at all or losing social roles and status – some of which can lead to conflicts. The older person with dementia can come into conflict with practitioners about a range of options facing them [16]:

- Living at home at risk or moving to a care home.
- Following advice on diet when swallowing difficulties begin or declining a pureed diet that will reduce the risk of aspiration pneumonia.
- Remaining active despite the risk of falling or restricting activity to reduce falls.
- Driving or losing the driving licence. Loss of the right to drive is becoming a major practical and psychological problem for many people with dementia in the developed world [17].

26.3 Challenging Behaviour in Dementia

Understanding behavioural and psychological symptoms in dementia is important to avoid risks of worsening functional impairment, overmedication (especially with antipsychotic medication), relocation to a care home and elder abuse. ‘Risky’ behaviour is especially associated with fronto-temporal and Lewy body dementias (as is loss of insight, but distinguishing poor insight and judgement from stoicism or even courage can be difficult) [11]. Agitation or aggression may indicate pain (which the individual cannot describe or localise), infection or misinterpretation of others’ actions. ‘Wandering’ may have meaning for people with dementia [18], as a form of re-familiarisation with the environment, or of ‘window shopping’. A high proportion of people with dementia who have behavioural and psychological symptoms experiences significant improvement over 4 weeks with no specific treatment. Thus,

watchful waiting is the safest and most effective therapeutic approach unless there is severe risk or extreme distress [19]. A safety-first approach may lead to avoidable constraints being applied, like sedation. A pragmatic approach may see benefits in walking for mood and sleep and arrange the environment to make ‘wandering’ safer. A right-based stance will accept risks and work around them, as long as the individual has capacity to make decisions – including wrong ones. Such risk management needs to include support for family or other carers to reduce their risk of breakdown or crisis.

26.4 Carers and Risk

Professionals tend to look at risk in a generalised way [20], whilst people with dementia and family carers take a more personalised view and also engage in self-regulation of risky behaviours, for instance, giving up driving or working with hazardous tools. The risk themes which are currently debated are the ‘big’ topics of diagnosis, driving, money management and moves into long-term care. There is much less discussion about everyday issues like leaving a person with dementia alone in the house or what to do about their smoking. For example, sometimes problems arise for carers when eating out with the person with dementia, which they deal with pragmatically or by avoiding going out [21]. This emphasis is still on ‘big decisions’ rather than smaller everyday decisions and typifies wider debates about rights to take risks versus the ‘safeguarding’ of vulnerable groups. For practitioners a key resource is likely to be other ‘experts by experience’ such as carers’ groups in the locality. While some of these are dementia focused, in some areas more generic groups potentially offer emotional as well as practical support with day-to-day dilemmas.

26.5 Putting Risk in Its Place

Both practitioners and family carers now have a clearer legal framework for action in England and Wales in the Mental Capacity Act 2005 (which we will discuss further in the next chapter). The Care Act 2014 provides a further set of principles to guide service commissioning of services to promote well-being and to support family carers. However, risk is situated in people’s own experiences and expectations [22], so ‘risk’ assessment is context specific and necessarily person centred. We need to be aware that an emphasis on risk enablement rather than harm minimisation may not fit all professional assessment systems, even though national risk guidance is multi-professional [8]. Greater community awareness of dementia (and its risks) and the involvement of other family members, friends and neighbours in supporting an individual with dementia will widen the debate about risks. And in a super-diverse society, we cannot assume that dominant notions of risk are shared by people from different backgrounds who may have very different views on autonomy and independence.

26.6 A Risk ‘Heat Map’ for Primary Care

Figure 26.1 below, taken from the UK Department of Health’s Risk Guidance for Dementia [17], sets out methods for conceptualising risk as a matter of assessment and of judgments about importance and likelihood. The ‘heat map’ shown in Fig. 26.1 provides a framework in which to consider each potentially hazardous behaviour or activity as a balance between quality of life and risk. There is no scoring system, but it can be used to trigger a discussion between the key parties involved. A strategy for mitigating risks can be worked out using the ‘heat’ map with a range of professionals or supporters as well as with the person with dementia (if this is possible) and with family carers. This may helpfully be used in collecting information (how often does the person with dementia leave a lighted cigarette unattended, when and where?) and making an assessment (the person may enjoy smoking and it may be calming) and in the sharing of different perspectives (the right to smoke may be fiercely contested and present risks of harm to others).

In primary care, there may be opportunities to influence such assessment and risk management through knowledge of the person with dementia and also of family carers’ possibly different viewpoints. The role of the primary care practitioner may be to offer opportunities for discussion, forms of mediation and some clarity over the legality of decision making and sometimes to act as an expert opinion provider

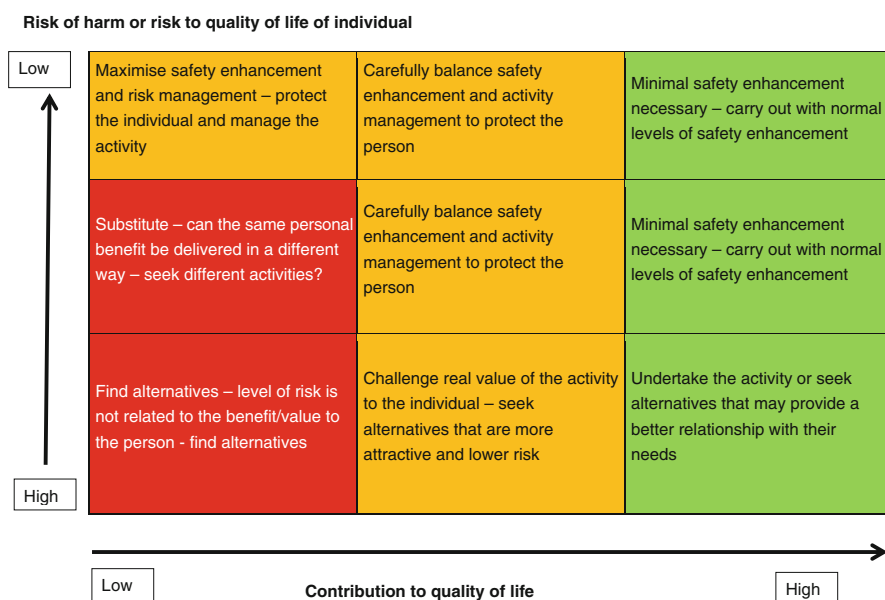


Fig. 26.1 Risk ‘heat map’ (From Manthorpe and Moriarty [8]; contains public sector information licensed under the Open Government Licence v3.0 <https://www.nationalarchives.gov.uk/doc/open-government-licence/version/3/>)

when a patient is at the difficult stage of becoming less able to understand information and to act in their own best interests.

In the United Kingdom, the risks of exploitation of people with dementia are being increasingly recognised [23] and practitioners should be alert to signs of this and all other forms of elder abuse and familiar with local safeguarding policies and procedures. Interestingly the term ‘adult at risk’ is used in the Care Act 2014 (England) to replace ‘vulnerable adult’ suggesting a new emphasis on risk as a form of social classification. For primary care practitioners, the use of the word ‘risk’ therefore needs to be used with caution and applied to specific situations in which likelihood and severity of harm or gain are identified. For example, a family carer consulting her GP may talk in some distress of her relative’s risky behaviour, but elucidation of this is warranted.

Close multi-professional working may assist in the analysis of the presenting risks but also in the negotiation of a support plan, its monitoring and review. As we have observed above, behavioural symptoms that are difficult to manage are often cast as presenting risks, and primary care practitioners may be the first professionals to be informed of these. Theirs is a key role in securing expert support, which may range from specialist interventions by secondary care practitioners to peer support for people with dementia and for family carers.

26.7 Conclusion

Understanding and managing risk are central to provision of support and care for the individual with dementia, their family and other carers. Some of this risk is intrinsic to the underlying pathologies, some to the social and cultural habits of our time and some to the different perspectives of professional and a diverse public. Practitioners of all disciplines will need knowledge about the biological basis for dementia, its psychological consequences and its social context, to provide adequate and tailored support.

26.8 Audit Suggestion

Use the ‘heat map’ to think about how you would respond to these scenarios involving people with dementia, balancing quality of life against risk:

- Mr. A’s family tell you that he is determined to do things alone and often goes to Post Office, but frequently gets lost on the way and, because he does not dress appropriately for the weather, sometimes gets very cold.
- The children of Mrs. B – who lives alone – complain to social services that she likes meeting people when she goes round the town, but has invited a new ‘friend’ home, and they think she is being exploited.
- Mrs. C’s spouse knows that she has paid someone who called at the house to clean their windows, but no cleaning has been done and he thinks she has been conned.

Key Points

- A ‘false-positive’ diagnosis of dementia will jeopardise patient and family trust in practitioner judgements.
- ‘Risky’ behaviour is especially associated with fronto-temporal and Lewy body dementias.
- The UK Department of Health’s Risk Guidance for Dementia conceptualises risk as a matter of assessment and of judgments about importance and likelihood.
- Close multi-professional working may assist in the analysis of the presenting risks but also in the negotiation of a support plan, its monitoring and review.

References

1. Iliffe S, Manthorpe J. The hazards of early recognition of dementia: a risk assessment. *Aging Ment Health*. 2004;8(2):99–105.
2. Williams SJ, Gave J, Calman M. *Health, medicine & society: key theories, future agendas*. London: Routledge; 2000.
3. Beck U. From industrial society to risk society. In: Featherstone M, editor. *Cultural theory and cultural change*. London: Sage; 1992. p. 99.
4. Department of Health. *National dementia strategy living well with dementia: a national dementia strategy*. London: Department of Health; 2009.
5. Department of Health. *Prime Minister’s challenge on dementia delivering major improvements in dementia care and research by 2015*. London: Department of Health; 2012.
6. Walker AE, Livingston G, Cooper CA, Katona CLE, Kitchen GL. Caregivers experience of risk in dementia: the LASER-AD study. *Aging Ment Health*. 2006;10(5):532–8.
7. Gordon DS, Carter H, Scott S. Profiling the care needs of the population with dementia: a survey in Central Scotland. *Int J Geriatr Psychiatry*. 1997;12:753–9. Carers value people to listen to them and respond personally.
8. Manthorpe J, Moriarty J. ‘Nothing ventured, nothing gained’: risk guidance for people with dementia. London: Department of Health; 2010.
9. Mythen G, Walklate S. *Beyond the risk society: critical reflections on risk and human security*. Buckingham: Open University Press; 2006.
10. Krieger N. Embodiment: a conceptual glossary for epidemiology. *J Epidemiol Community Health*. 2005;59:350–5.
11. Gordon M, Goldstein D. Alzheimer’s disease – to tell or not to tell. *Can Fam Physician*. 2001;47:1803–8.
12. Johnson H, Bouman W, Pinner G. On telling the truth in Alzheimer’s disease: a pilot study of current practice and attitudes. *Int Psychogeriatr*. 2000;12(2):221–9.
13. Burns A, Buckman L, on behalf of the Timely Diagnosis of Dementia Consensus Group. *Timely diagnosis of dementia: integrating perspectives, achieving consensus*. London: BMA/NHS England; 2013.
14. Le Couteur DG, Doust J, Creasey H, Brayne C. Political drive to screen for pre-dementia: not evidence based and ignores the harms of diagnosis. *BMJ*. 2013;347:f5125.
15. Prince M, Bryce R, Ferri C. *World Alzheimer’s report 2011. The benefits of early diagnosis and intervention*. London: ADI; 2011.
16. Patterson C, Rosenthal C. Living a little more dangerously. *Lancet*. 1997;350:1164–5.
17. Mason A, Wilkinson H. Whose hands are on the wheel? Experiences of giving up driving. *J Dement Care*. 2001;9:33–6.

18. Dewing J. Screening for wandering among older people with dementia. *Nurs Older People* 2005;17(3):20–2, 24.
19. Alzheimer's Society. Optimising treatment and care for behavioural and psychological symptoms of dementia: a best practice guide. http://www.alzheimers.org.uk/site/scripts/download_info.php?downloadID=609.
20. Carr S. Enabling risk, ensuring safety: self-directed support and personal budgets enabling risk, ensuring safety. London: Social Care Institute for Excellence; 2010.
21. Manthorpe J. Eating out: dementia carers' views on the pleasures and pitfalls. *J Dement Care*. 2002;10:26–7.
22. Kemshall H. Risk rationalities in contemporary social work policy and practice. *Br J Soc Work*. 2010;40(4):1247–62.
23. Samsi K, Manthorpe J, Chandaria K. Risks of financial abuse of older people with dementia: findings from a survey of UK voluntary sector dementia community services staff. *J Adult Prot*. 2014;16(3):180–92.