Living alone with dementia: risk and the professional role

Helen Gilmour describes research that looked at risk in relation to people with dementia living alone, sometimes in remote communities, and the informal networks which help sustain them.

The number of people with dementia is increasing alongside the social trend of a greater proportion of the population living on their own. But there appear to be few studies that focus on the theme of people with dementia living alone. The related area of risk associated with this client group also appears to be relatively under-researched, particularly from a multi-disciplinary perspective. Can professionals work as partners with people with dementia and their families? Can there be a consensus on what constitutes risk and how it can be addressed?

This article summarises a qualitative study of ten people with dementia who live alone in their own homes. The views of these individuals, their families and care staff, GPs, district nurses and social workers are described and analysed, providing insights into different perceptions of risk. The aim of the study was to explore the concepts of risk in the context of the social circumstances, lifestyle, health status, and range and intensity of services utilised by a small group of people with dementia who lived alone in a rural area and who had been identified from an earlier study (Gilmour 2002).

The objectives of the study were to illuminate the daily experiences of these people, to identify their awareness of risk as well as perspectives on risk held by their principal family carers, various care staff and health and social services professionals who supported and sustained them in their present living arrangements. It was also hoped that the study might identify why these people managed to remain living in their own homes and what health and social services developments might be needed to sustain other people with dementia who, in similar circumstances in the future, might also wish to remain at home.

The findings and discussion highlight issues relating to assessing and managing risk and both problems and opportunities related to living alone with dementia. In this study no incidents of major harm were reported and daily contact with others was considerable. However, resources and support are needed to enable professionals, families and people with dementia to achieve a sense of shared negotiated responsibility for risk-taking.

Background

The research reported in this article carries on from a larger study of people with dementia living in a dispersed rural area in the south west of Northern Ireland (Gilmour 2002, Gilmour et al 2003). This area has a total population of 57,527 people and 7,961 people over the age of 65. Within Northern Ireland, health and social care services are delivered, unusually in the context of the rest of the UK, within an integrated structure (Campbell and McLaughlin 2001). This earlier, mainly quantitative research itself followed on from a study undertaken in the same location ten years previously (Gilmour and Bolton 1991).

Literature review: risk

Risk can be linked with the concepts of harm or danger or as a chance to gain benefits in a situation where harm is also possible. Risk-taking for people with dementia extends beyond that of physical safety to embrace psychological and social care dimensions. Clarke (2000) discusses how the construction and definition of risk by health and social care agencies differs from perceptions held by people with dementia and their carers. While professionals emphasise the physical aspects of safety, maintaining self-identity and interpersonal relationships are more important to people with dementia and their families. Clarke concludes that there should be a sharing of the different perspectives, which should result in improved professional practice.

Alaszewski and Manthorpe (2000) examined the way in which district nurses made decisions about risk and professional responsibilities while working with older people. They concluded that education and training could improve practice. In an examination of the role of psychiatric nurses working with people with dementia and their family carers, Adams (1999) identified a lack of partnership. He suggests that this could be improved through research and practice and raises the unresolved issues of power and control.

Alaszewski et al (2000) discuss an ethical framework for nurses managing risk, drawing on the theoretical approaches of utilitarianism, human rights and virtues. They conclude that the virtue approach, which embraces risk positively and creatively, pro-
vides the opportunity to empower nurses and users of the health service.

There are few research studies concerned with risk assessment of older people with dementia, although Jacques (1992) sets out a model outlining the key factors when considering the decision-making abilities of the person with dementia. It highlights three intervention choices:

- leave the person in charge/accept risk
- persuade the person to accept help/lessen risk
- take control by compulsory means.

Woods (1999) commends the use of needs assessment scales such as those described by McWalter et al (1998) that can allow for individuals with dementia to self-report as a way of promoting independence and wellbeing.

Research
In this study, it was viewed as particularly important to allow people with dementia, and their carers, time to express their views in their own words, as a way of them understanding many of the hidden issues and problems which may be associated with the largely under-researched area of people living alone with dementia. A series of open questions was used to elicit data from the person with dementia and family carer in the following areas: current daily circumstances, health, awareness of diagnosis, involvement of family and neighbours, contentment, concerns and risks and how these were dealt with, care package and views on the future. This involved a visit to the person with dementia in his or her own home. The willingness to engage in discussion was monitored throughout and the interview was terminated if the person appeared tired or uninterested.

Twelve family members (from nine families) were interviewed separately. Six GPs were interviewed and four district nurses were interviewed in relation to five people with dementia whom they visited at least every month. Two of these nurses also made comments about two further people they also knew professionally but visited less regularly. Two social work assistants, one social worker and three social workers who carried care management responsibilities were interviewed. Professionals and care staff were asked about the diagnosis and referral, their views on care plans, identification of risks, professional dilemmas and how these are dealt with, and views on the future.

Results
Two men and eight women with dementia were included in this study. Their average age was 83.3 years, with ages ranging from 74 to 93 years. Only one person was unknown to social services. Five people resided in a main town, three lived in villages and two lived in remote country areas. All but two had family living within the same geographic area and had daily contact with them. Nine had care packages managed by social workers employed by local social services. Six people had been comprehensively assessed and were care managed, although there was no evidence of the use of explicit risk assessment tools for people with dementia.

People with dementia
Eight of the people with dementia were able to respond in meaningful ways to describe their circumstances although none of them, unlike the other respondents, used the word “risk”. Six indicated frustration with their memory at some stage in the interview. This involved a visit to the person with dementia in his or her own home. The willingness to engage in discussion was monitored throughout and the interview was terminated if the person appeared tired or uninterested.

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and I don’t like it. It’s hard getting older.’

Two women appeared to resent the help they received and wanted to be left alone as they felt they were competent with household chores and personal care: ‘I could do without it.’ The majority appeared accepting of care staff involvement although in the more complex care plans it was sometimes difficult for them to ascertain who was involved and for what reasons: ‘Different people come in. I can’t remember their names. There was a different one this morning.’

A 93-year-old woman described very convincingly and at length the tasks she had undertaken that day including how she had made the curtains. On being asked how she slept at night she said: ‘I get up at night to check on my parents.’ A 91-year-old woman appeared uncertain about where she was living or who was supporting her. ‘I wish I had my mother now. I miss her more than ever.’ One woman talked about currently driving her car even though her family had sold it over a year earlier.

The interviews included a discussion on how the people with dementia spent their days and many comments indicated a search for structure and meaning to their lives: ‘I like to walk. You have to do something.’ This desire for usefulness was fulfilled for one woman by attending a day centre: ‘It’s like work. It gives you something to do.’ Another woman with less advanced dementia who carried out many household chores was rather pessimistic about the worth of these duties: ‘I keep very busy doing nothing.’ Some respondents expressed appreciation of the support of their family although there appeared to be an expectation of support: ‘Why shouldn’t he be good to me. Didn’t he get my place [a reference to a family farm]?’

**Family carers**

All the family members indicated that these people faced risks. The main types mentioned were heating, falling, managing money, road safety, getting lost and cooking. This daughter-in-law described the family’s concerns regarding the cooker and how they dealt with it: ‘Banana and tea towel in the oven and the smell of burning. We switched the cooker off at the plug and she never attempted to switch it on again.’ A daughter explained that outsiders also posed problems: ‘The tar worker [a person who laid tar on the driveway] brought her to the bank to get her money out’; and ‘We got a person who laid tar on the driveway’ brought her out many household chores was rather pessimistic about the worth of these duties: ‘I keep very busy doing nothing.’ Some respondents expressed appreciation of the support of their family although there appeared to be an expectation of support: ‘Why shouldn’t he be good to me. Didn’t he get my place [a reference to a family farm]?’

Lost pension books and bills were identified as a common problem and a carer expressed the difficulty of supervising finances in the following way: ‘There is no mid way for dealing with finances – either she is capable or incapable.’ There was evidence that the family members worked in conjunction with social services in addressing risks, particularly with regard to changing the heating system. In contrast to this shared responsibility, one son explained that his decision to keep his mother at home (she was assessed as needing 24-hour care but this could not be provided by social services outside a nursing home) increased the possibility of risk: ‘I get into trouble when she falls.’

**Care staff**

Responses from paid workers tended to emphasise the importance of locality in terms of assessing and managing risk. One carer pointed out that ‘wandering’ only became a problem when the person moved out of his village to a formal care setting: ‘Suppose he went out as he can go out and some neighbours saw him, they would take him back. It’s a close-knit thing. He was in … for respite and got out. Somebody must have left the door open. He was walking on the main road!’

This local perspective and lifelong knowledge was evident in many of the comments. For example, in relation to a man living in a remote area, his home help reported: ‘He goes across the road. All the locals know him and they slow down but I’m afraid of some stranger in a car.’ And: ‘He goes for a drink with a neighbour … I’ll find him on the floor in the morning but sure that’s how it always was.’

One carer used her life experience to interpret risk: ‘If I was 20 years younger I would probably worry more but now I think about what I would like for myself. I’d rather be found dead in my own house. He would never survive in a nursing home.’ This same carer appreciated that professionals also accepted a level of risk: ‘The first week out of hospital he just kept falling but then he got into his own way. It was good of them [the professionals] to allow this.’ Some carers also felt that they too could be at risk because of their role: ‘I used to lift her but I was at the Alzheimer’s training one night and they said you could hurt the patient and hurt yourself so after that I always wait for someone to help.’

**General practitioners**

All the GPs indicated that the person with dementia should, ideally, remain in his or her own home, despite risks posed. The following comments summarise a range of views: ‘There are risks but they are worth taking’; ‘There is always a risk with them. There are some periods of time when they are on their own and you don’t know what they are going to do’; ‘She would not be able to judge things but she would not want to be anywhere else.’ The lack of alternatives and respecting people’s wishes to remain at home were the main factors which made GPs accept such risks: ‘There is an old Irish saying, “There is no fair place like your own”’; ‘The nursing homes are not geared for care. We encountered a range of views: ‘There are risks but they are worth taking’; ‘There is always a risk with them. There are some periods of time when they are on their own and you don’t know what they are doing’; ‘She would not be able to judge things but she would not want to be anywhere else.’ The lack of alternatives and respecting people’s wishes to remain at home were the main factors which made GPs accept such risks: ‘There is an old Irish saying, “There is no fair place like your own”’; ‘The nursing homes are not geared for care.’

One GP had recorded his concerns on the patient’s notes and had obviously discussed it with the person with dementia: ‘Several times we have approached him to say that he is at risk living by himself – when the home help goes home at nights there is no one going to see him till the morning. So if he fell out.
of bed, particularly in the winter months, if he went outside, you know, he is at risk of not only fracturing himself but of hypothermia. I have approached the subject a few times but he is adamant that he doesn’t want to go anywhere.’

District nurses

Falling was the most common problem identified by the district nurses. Perhaps this was because nurses were often involved in the follow-up in such cases: ‘When she knocks her leg we are in for a week and then it settles down.’

Some nurses were keen to establish rules about risk management, reflected in the following response: ‘Constant supervision is a must for her, especially when she is in her own home with an open fire. The fireguard should be in place at all times.’

Ensuring adequate nutrition was a concern mentioned by three of the district nurses: ‘We have got her supplements and have done her bloods recently.’ Two nurses acknowledged the role of social services in reducing risk. One said: ‘Before the care package was in place she used to be upstairs. We now have a hospital bed downstairs and it is much safer.’

As well as other professional groups there appeared to be a willingness to accept a certain degree of risk as a sound ethical position: ‘I know that there is a risk but we have to accept that there is a risk but that it is her wish to remain at home.’

Social workers

Social work staff generally echoed the types of risks mentioned by the family members: heating, falling, managing money, wandering and cooking. There were no separate risk assessment forms completed for any of the people in this study, but some evidence of working with family members in addressing identified risks was apparent: ‘It took a while to work with this family and get the money to get the cooker changed.’ One social worker, however, indicated that partnership in this area did not always work: ‘Afternoons are a risk area. We are not able to provide services from 1.30 onwards. It would have to be a nursing home. It is the family’s responsibility. If you have advised them, what more can you do?’

The same social worker felt that there was a lack of trust in the relationship with the family member: ‘I have learned a lesson – do not believe all that is told to you.’ A number of examples were used to illustrate this point: ‘They don’t use the hoist. Her bedroom would have to be revamped and they think it is degrading for their mum. All the risks have been pointed out to them.’

Discussion

The Alzheimer’s Society (2000) states that there is no such thing as a risk-free environment and any discussion of the subject is necessarily complex (Waterson 1999, Stevenson 1999). The tension between maximising independence and minimising risk is not unique to this geographic area (Cox and Minter 1999, Stevenson 1999).

The research uncovered some of the main areas of risk as identified by family and professional caregivers. The main areas of risk to emerge from this study were heating and cooking, falling, getting lost and managing money. These findings reflect some of the areas covered by the Alzheimer’s Society advice leaflet and this should be made widely available to carers and professionals (Alzheimer’s Society 2000).

None of the people with dementia showed concern about the practicalities of risk, although two people indicated that services were unwanted and unnecessary. Increased forced dependence and disempowerment may be an associated emotional risk that needs to be further explored. Bond et al (2002) argue that a diagnosis of dementia can lead to professional judgments about lack of insight. This results in increased professional anxiety and depersonalisation of the person with dementia. Professionals with their expert knowledge on disease processes and emotional responses to ageing and reduced autonomy need to balance their views with the expert knowledge of the person with dementia and family carers. In-depth knowledge is required about personality, past lifestyle and community supports.

An important finding from the study was that no one reported any major incidents of harm, although potential risks were evident. For example, one man did get lost but neighbours helped with surveillance; food items were burned but there were no fires and the cooker was subsequently changed; a bank employee reported a minor incident involving potential financial abuse. Ironically, when a man was admitted to respite care he appeared to be more at risk when he left the unit (the paid carer reported that he was ‘found wandering in a main road’) than when he was in his home environment where he was well known and could be directed home again. Should risk assessment be based on the actuality of an adverse event or on the assessment of professionals and family carers of the likelihood of an event? Perhaps single events that cause concern can lead to an over-estimation of risk.

In this study there appear to be two main preventative factors which minimised harm. First, there was the concern and observation of people known to the person with dementia who were able to put the risk in context. This knowledge meant, for example, that a paid carer was able to accept that one man may spend the night sleeping on the floor after a drinking session because that is ‘how it always was’. One discerning bank employee contacted family members because of her suspicions that things were not right when a stranger accompanied the person with dementia into the bank to withdraw money. Perhaps people with dementia living in a stable, rural environment where neighbours and businesses have known them over a long period are less vulnerable to some types of harm.

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Another important factor relates to levels of contact by others in the day-to-day lives of the people with dementia. All these people had daily contact with others, whether family members, care staff or neighbours, a finding similar to that of Wenger (1994) and Wenger et al (2002). Thus, a son who had called in at his mother’s home managed to detect the smell of burning items before the situation became disastrous.

There appeared to be relatively high levels of supervision for all the people and in most situations there was agreement and co-operation between the person with dementia, family members and social services in addressing potential risks. For these reasons the ten people studied may not be representative of others who are socially and environmentally isolated and may therefore be at more risk. Moore (1996) points out that, although the acknowledgement of risk is an obvious starting point in the assessment procedure, the definition of specific problems associated with risk is often overlooked.

Even though there were no major incidents of harm, the study does point to some complex ethical dilemmas in addressing risk management. In one situation there were clear tensions as to who was responsible if harm occurred. Health and social services’ assessment of one woman indicated that she needed 24-hour care which, due to limited financial resources, could only be provided in a nursing home. Her son felt that such a move would ‘kill her’ and so accepted responsibility for the period when care could not be provided either by social services or the family. It was acknowledged by a social worker that: ‘It is the family’s responsibility. If you have advised them what more can you do?’ Yet her son complained: ‘I get into trouble when she falls.’ The ensuing debate about whether a hoist required to safeguard the health of care staff can or should be used, perhaps against a family’s wishes, illustrates another example of the complexities of delivering care in the community. Rights, risks and responsibilities need to be balanced according to different perspectives.

For these reasons the words ‘partnership’ and ‘empowerment’, which are often quoted in policy and academic literature in relation to community care, need to be translated into meaningful action. It takes time, resources and support to enable professionals, family members and people with dementia to work towards a shared, negotiated sense of responsibility and decision-making. Such complicated decisions should take account of legislation such as the 1998 Human Rights Act and should never be made in isolation by one professional group or person (Jacques 1992). Resolving dilemmas in relation to risks and people with dementia living alone requires careful weighing up of the likely benefits and harms. This should include a judgement about the emotional and social aspects of the situation as well as the physical (McDonald 1999, Stevenson 1999, Clarke 2000). Grassroots staff need support from their managers, team colleagues and other professionals to be able to deal with the pressures arising from resource limitations, accountability and possible litigation (Alaszewski et al 2001, Gallagher et al 2002). Finally, more needs to be done to disseminate and advance the findings of this and other research which is based on the lived experiences and views of people with dementia and their immediate networks where, despite complexities, anxieties and limitations, a person with dementia from the study could say with sincerity and conviction: ‘It couldn’t be better.’

Conclusion and recommendations

This study describes a range of issues faced by people living alone with dementia in a rural area where there are no specialist dementia staff and explicit risk assessments for people with dementia are not commonly used. Immediate resources are needed for these service and professional developments. The research points to the invaluable and often unacknowledged contribution of family members, neighbours, care staff and members of the community such as shopkeepers. It would appear that this in-depth knowledge of the person with dementia often provides an important backstop to decisions made about risk. Future development of services should therefore take into account the significance of community support networks that can enhance the role of informal carers and other citizens.

This research also emphasises the importance of working together within primary care in relation to assessing and managing risk. Increased public expectation and a more litigious health community will make multi-disciplinary assessment, care planning and review essential. Developing social work attachments to primary care may facilitate this.

It is important that where interventions take place, professional staff are informed by research and equipped with the skills and confidence to enter into negotiations with their colleagues, people with dementia and their families about care at home and attendant risks. This will require a further exploration of the analysis and management of risk in health and social care with additional resources in terms of training and professional development. Further research is vital into the emotional risks of disempowerment associated with service provision that addresses practical safety issues but results in forced dependency and lowered self-esteem.

References


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