Ethics and the Care of the Elderly

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Key Points

- While people across all cultures agree about the value of respecting elderly people, levels of elder abuse in most communities are high.
- Elderly people require access to appropriate care in all settings and hospitals need to be more ‘friendly’ to elderly people.
- In many cultures, dementia is seen as a form of mental illness rather than a neurological condition, and this means that it is widely stigmatized and often hidden.
- It is possible for elderly people to express their future wishes in advanced care plans so that their wishes will be respected, even if they develop dementia.
- There is a need for increased advocacy for the needs of elderly people.

Case Study

MS is an 82-year-old Indian man living with his son and daughter-in-law in a large city in Australia. He was brought to Australia by his son 3 years ago after the death of his wife as neighbours reported that he was not being cared for well. He now lives in a self-contained flat under his son’s house and has gained permanent citizenship—which means he is eligible for government-subsidized healthcare.

Both MS’s son and daughter-in-law work and are away from home from 8 a.m.–7 p.m. The old man is left alone by himself during the day and spends his day pottering around his flat. He also appears to drink several whiskeys each day. Recently he has become more confused. He has been in some shouting matches with his son and on one occasion placed his hands around his son’s neck. He

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usually supervises the grandchildren at home each day after school but has become more irritable and angry with them.

MS has a visit each day from a home-care provider who helps with showers and reminds him to take his medications. Recently, the care provider has suggested that he should start going daily to a respite centre at a nearby residential aged-care facility (RACF) or consider full-time placement in a RACF. The son and daughter-in-law would be happy for him to have respite care but would like to avoid RACF placement if possible. Nonetheless, they have been urged to start the paperwork for this, in case their options become limited. They have looked into paying for full-time carers, who are too expensive for them, and they have also looked into getting a family member from India to help care for MS. They cannot afford for either wife or husband to stop working.

Both feel that the family should be caring for MS but cannot see a way to manage this in their current living situation.

In this chapter, we will look at ethical issues in the care of elderly people. Definitions of who is 'elderly' vary from population to population. In Australia, the definition of the elderly currently refers to people aged over 65 (although some government departments use the population of people over 70 instead). Aboriginal people in Australia aged over 50 are regarded as elderly. In countries such as India and Malaysia, people are regarded as elderly when they are 60 or over.

Ethics can also be defined in a range of different ways: one approach is that the field of ethics looks at what we *should* do. If we think about it in this way, then the aim of this chapter is to understand how we *should* provide care for the elderly. In the case study above, the family of MS are faced with the ethical question of how they should care for the old man. One of the hallmarks of ethical questions is that people feel strongly about the outcomes [1]. It is possible that no matter what approach his family find for the care of MS, they may feel guilty themselves or be told by family members or those outside the family that they have done the wrong thing.

As a general principle, the clinical care of an elderly person should be based upon an honest and sympathetic attempt to come to terms with the individual problems that each old person and their family face. This requires good communication skills, adequate time, the provision of appropriate resources (including hearing devices and translators where necessary), good clinical skills and knowledge and some insight into the living conditions of each elderly person, as well as good faith on the part of the doctor or therapist in approaching the patient's difficulties with a patient-centred focus. There is also a tradition in geriatrics that the best way of understanding a patient's living condition often includes home visiting as a way of understanding his or her social and environmental context.

19.1 Respect for the Elderly

Most societies pride themselves on the way that they provide care and respect for elderly people. Yet in all societies, there are elderly people who do not have access to family supports and who may not receive the social care they require. For example, Janice Reid has written about the role of elderly people in aboriginal societies (the Yolngu people) in Northern Australia:

> The treatment and status of the elderly is probably no more uniform in Aboriginal society than it is in Western societies. Differences between the fortunes of individual elders largely reflect their personalities and their differential location in the economic, political and social structures. Some old Yolngu today have been able to take advantage of the direction of social change to enhance their status and material security; others have been bypassed or marginalized by the forces of modernization and seen their fortunes dwindle with their age…[A major theme] relating to the care of the aged seems to be the importance of having someone willing to take on a caring role. 'Big men' have young wives or caring children; many women have their children or co-wives, but aged widows, widowers or bachelors may have had no-one to nurse them at the end [2].

The same is likely to be true of most other societies—elderly people who have built up stores of social capital in their lives, through families, friendship and other social structures around them, are likely to do well as they age and be supported and respected in the ageing process. People who have become isolated in their lives—whose families have died or lost contact, who have been heavy drinkers or experienced mental illness or whose families are unable to manage for some reason—are not likely to have good social resources as they grow older.

Trajectories of ageing are greatly mediated by cultural differences. For example, in India, the notion of kinship stipulates that it is the duty of a child—particularly a male child—to provide support for parents in their old age, traditionally in the form of co-residence. About 60% of elderly men, and 25% of elderly women live with their spouse, children and grandchildren; 12% of men and 45% of women live in the same situation but without their spouse. About 2% of elderly men and 10% of elderly women live alone [3].

Living with children and grandchildren gives older people social and financial support, as well as providing them with a social role. These advantages are missing for those who live alone but also for those who live only with their spouse (20% of elderly men and 11% of elderly females in India) [3]. The difficulty that comes from elderly couples living separately to their families is not something that is discussed greatly in the West, where couples living alone are seen as almost the ideal living arrangement for the elderly.

19.2 Elder Abuse

To escape from the experience of abuse is one of the reasons why elderly people may want live alone. Elder abuse is both a consequence of the increasing powerlessness of some elderly people as they age and is a reflection of wider experiences of family abuse in most societies, including such forms of abuse as child and spousal abuse.

Elder abuse is sometimes divided into:

- Financial abuse
- Physical abuse

- Sexual abuse
- Psychological abuse
- Social abuse
- Spiritual abuse
- Neglect

Of course, one form of abuse can easily lead to another, such as when an elderly person is asked for money, refuses and then is pushed over or physically abused.

Elder abuse is unfortunately common. In a study of elderly people in New York, the past-year prevalence of elder emotional abuse was 1.9%, of physical abuse was 1.8% and of neglect was 1.8%, with an aggregate prevalence of 4.6%. Emotional and physical abuse were associated with being separated or divorced, living in a lower-income household, functional impairment and younger age. Neglect was associated with poor health, being separated or divorced, living below the poverty line and younger age [4]. In a community-based study in urban Chennai of 400 community-dwelling older adults, the prevalence of mistreatment was found to be 14%. Chronic verbal abuse was the most common followed by financial abuse, physical abuse and neglect. A significantly higher number of women faced abuse as compared with men, adult children, daughters-in-law, spouses, and sons-in-law were the prominent perpetrators [5].

19.2.1 Hospital Care of the Elderly

Elderly people are hospitalized at higher rates than young people, have longer average admissions and have higher rates of complications. Yet acute care hospitals are often said to provide an inappropriate setting for the care of elderly people. As Nichol and Wilson note:

> The acute hospital is a dangerous place for frail elderly people, which should act as a stimulus to improving the safety of patients through better hospital design, improved staffing levels and mix and improving standards of catering and cleanliness. [6].

While hospitalization may be dangerous for elderly people in itself, lack of access to hospitalization may also be a problem, as may be lack of access to appropriate care within hospitals. Care in the hospital system is often accessed through long waits in crowded waiting rooms, uncomfortable and disorienting stays in emergency rooms and long periods of waiting on trolleys in corridors. Inadequate public hospital infrastructure in many countries means that there is sometimes little that can be done to alleviate these stresses. In some countries, the government has tried to improve the experiences of elderly people in hospitals through policy, for example, the Indian government has mandated that elderly people should be able to wait in separate queues and have some beds reserved for them [7].

In the United States, emergency departments specifically designed for elderly people are now opening in many places. These aim to decrease noise and sensory overload, increase day/night orientation and decrease the rates of falls and disorientation through better design. Existing emergency departments can also be made more 'geriatric-friendly' through attention to factors such as noise and lighting, decreasing falls risks, education of staff about recognition of delirium and management of cognitive deficits and through provision of elderly liaison nurses and increased allied health services to improve care and better coordinate discharges [8].

19.3 Dementia

The leading risk factor for dementia is increased age. As elderly people age, their risks of dementia rise, and as societies throughout the world age, the prevalence of dementia will continue to rise. In the Asia-Pacific region, the number of people with dementia is predicted to increase from 23 million in 2015 to almost 71 million by 2050. That means that by 2050, more than half of the people with dementia worldwide (135 million) will live in this region [9].

Discussions of the ethics of dementia care in Western countries include considering when people should transfer care from families to institutional settings, how people with dementia should be managed in acute care settings and how the decisions that someone takes before they have dementia can carry over to when they are no longer competent to make decisions. As with other elderly people, issues of powerlessness, exploitation and abuse are also important with this group of people.

Shaji has suggested that the following issues are common to dementia care in developing countries:

1. Dementia is a hidden problem and is underestimated.
2. Dementia is not thought of as a health condition.
3. Dementia is a stigmatized condition.
4. Traditional care is under strain.
5. The problem of care burden is not acknowledged properly.
6. Healthcare systems are not sensitive to the needs of people with dementia.
7. Lack of development of services [10].

Shahji's discussion of his first three points centres largely on the issue of stigmatization. The behavioural disturbances that occur with dementia may often be interpreted as 'craziness', and so dementia is stigmatized as part of a wider stigmatization of mental health in general. A common response is to hide people away, but with inadequate resources available for respite care, people with dementia may be looked after by family members or untrained servants when trained carers are unavailable. For many people, 'The simplest way out is to lock them up in their houses' [11].

Another of Shaji's points is that traditional care is under strain. As Western lifestyles emerge in developing countries, family members may migrate away, and it is more common for women to work and for families to break up. This places elderly people at risk of having no one to care for them.

Institutional care is starting to be more common in Asian countries but is still widely stigmatized. In Australia, ethnic groups such as people with Chinese and Indian heritage continue to care for elderly people at home—often until late in the disease process. Institutional care is probably less stigmatized in these groups in Australia than it is in their home countries, and people from these ethnic groups appear to be finding that there is a place for high-quality institutional care.

An alternative to institutional or family care is also possible in countries where labour is affordable. Many middle-class or well-off families can afford to hire 24-h care by trained care workers in the home. Such care is simply not possible in Western countries because of the cost. This sort of care may provide a more culturally appropriate care model for those who can afford it than institutional care.

In Western countries, institutional care has a particular role to play in people with dementia—including those with behavioural and psychological symptoms of dementia (BPSD). Among people with dementia in India, BPSD are common and cause significant distress to patients and carers [12]. And yet BPSD should be manageable in most cases with adequate education about behavioural interventions, appropriate medication and provision of respite for caregivers.

19.4 People with Impaired Mental Capacity

People who cannot make decisions for themselves may be referred to as having ‘impaired capacity’ or ‘decreased mental competence’. We will use these terms interchangeably.

The terms ‘capacity’ and ‘mental competence’ refer to a person’s ability to take in information that is important for some reason, understand it, come to a decision about what should be done and express that decision. Different cognitive abilities are required for different types of information and different types of decision. For example, a person’s ability to make a will (the so-called testamentary capacity) depends upon a person having long-term memory so that they know who they have debts to and an understanding of their current possessions and financial situation. By contrast, a person’s ability to consent to an operation requires the ability to understand the proposed procedure and weigh up the risks and benefits of undergoing it.

People with dementia do not automatically have impaired capacity for all decisions. The approach to judging whether a person has impaired capacity for a particular decision is based upon firstly talking through the particular decision at hand and then also supplementing this information with a more general cognitive examination. It is important not to confuse the assessment of competence with the assessment of cognition—a person with mental illness may have excellent cognition but may not be competent (e.g. if their decision is being driven by a delusion). A person with poor cognition may be competent for some decisions (such as the appointment of a wife or child as their surrogate decision-maker). However, among elderly people, where the prevalence of dementia is high, disorders of competence and cognition often go hand in hand.

There has been an ongoing debate in ethics as to whether the degree of competence that a person needs to make a decision depends primarily on the complexity of a decision or upon the severity of the consequences of a decision. A useful approach is that the more complex a decision is, then the more cognitive skills are required to come to an outcome. However, the more severe the outcomes of a decision are, the more certainty the assessor should be in their judgement of the person's competence. For example, if a person has to decide whether their leg should be amputated—and it is clear that they will die if they do not—then this is in many ways a very simple decision, and many people with very limited cognitive status would be able to understand this choice. If, however, a person refuses the operation, then a consultant who is asked to assess their competence would want to be very certain that the person was competent, since the consequences of refusal would be so severe. It is important to note that there is no test or questionnaire that absolutely assesses a person's competence—and this assessment will always be to some extent subjective.

19.5 Who Can Make Decisions for People with Impaired Capacity?

If a person is found to be not competent to make a decision, then the usual practice in Western countries is firstly to search for a relevant advance care directive, and if one is not found, then proceed to make decisions through the use of a surrogate decision-maker [13]. Advance care directives are uncommon in many countries (see below) so the use of surrogate decision-makers is the more usual approach.

Different authors use different terminology around the concept of surrogate decision-making. In this chapter, 'surrogate decision-making' refers to any situation in which another person makes a decision for a person on the grounds of the person's lack of capacity. A 'substituted judgement' refers to when surrogate decision-makers attempt to use their own knowledge of the person who lacks capacity and to make a decision that the person would have made himself/herself. This process may also be called 'substituted decision-making'.

There are a number of ways that surrogate decision-makers can make decisions or assist in decision-making for people with impaired capacity. The organization 'Alzheimer's Australia' suggests that surrogate decision-makers can modify the decision-making process through a hierarchy of responses that escalate as the capacity of a person with dementia decreases [14]. Some of the ways that decision-making can be facilitated include:

1. Assisted decision-making, which may involve simple things such as taking the person to meetings and making sure they understand documents
2. Supported decision-making, which may involve exploring and explaining issues but allowing the person to make the final decision
3. Substituted decision-making, which involves making decisions on behalf of the other person

Both assisted and supported decision-making are important tools in helping people with dementia, but a caveat must include that they should not involve elements of coercion. In some jurisdictions, court-appointed guardians must make decisions ‘in a person’s best interests’ rather than through substitute decision-making.

The most natural people to make decisions for those who have impaired cognition are their close family members. Many elderly people trust their partners and family members to make decisions for them in the belief that the family’s decisions are most likely to reflect their own wishes and values [15, 16]. Family members do generally try to do the right thing for their loved ones and are often more accurate than physicians at predicting patients’ preferences for treatment.

However, family members may also have mixed motives—and it is relatively common to see younger family members exploiting elderly people who have diminished capacity by stripping them of financial and other assets, attempting to have them change wills in the relatives’ favour or acting in other ways that do not seem in the person’s best interests. Another way that family members sometimes appear to act against an elderly person’s interests is when a relative insists that ‘everything be done’ including futile surgery and other procedures, and this seems to be not for the patient’s best interests, but rather so that the relative can defend themselves from the judgement of other family members. Finally, families may often disagree about the care of an elderly relative.

In situations where there are no appropriate surrogate decision-makers, or where surrogate decision-makers do not appear to be acting in the elderly person’s best interests, it may be possible for a legal guardian to be appointed, including a public guardian where no suitable family member or friend can be found. In many jurisdictions, there is provision for separate management of financial and property matters and health and social matters. In some jurisdictions, such as India, guardianship of elderly people with dementia comes under mental health legislation (http://keralalaw.blogspot.com.au/2010/02/laws-relating-to-guardianship-in-india.html), whereas other jurisdiction such as those in Australia subsumes people with psychiatric illness, those with developmental disability and those with dementia under legislation based on impaired decision-making capacity rather than ‘mental health’.

Given the long-time interval required to settle many legal applications for guardianship, and the fact that increasing numbers of people have no suitable relatives available, it is not uncommon that people with impaired capacity have no one available to make decisions for them. In these situations, health workers need to rely on ‘common law’ arguments to justify treating people. Common law in many countries has provision to treat people without consent if doing so will save their life or save them from significant injury. This is sometimes used to argue, for example, that a person with impaired capacity but without a legal guardian should be held in hospital against their will, as they would be likely to come to major harm if they left.

19.6 Advance Care Planning

‘Advance care planning’ is the process whereby a person who is still capable of making decisions sets down their preferences for what should happen if they lose decision-making capacity. The idea of advance care planning started with decision-making around cardiopulmonary resuscitation and the provision of no-CPR orders. Advance care planning continues to be often linked with questions of end-of-life planning. In Western countries, there is a wide public support for the idea of advance care planning, and some types of advance care planning—such as decisions to withhold CPR—may be legally binding.

Non-Western countries often have different views of this. For example, Htut and colleagues interviewed elderly Malaysians about advance care planning and found that although the majority agreed on the importance of planning for future medical management and having open discussion on end-of-life issues with their doctor, they felt it unnecessary to make a formal written advance directive. According to Htut, ‘Most felt that the future was best left to fate or God, and none had made any contingency plan for severe future illnesses citing religion as reason for this view’ [17].

It seems unlikely that end-of-life decision-making, in the Western sense, will have much impact in cultures where end-of-life circumstances are thought primarily to arise from the will of God. However, advance care planning in other areas—such as financial planning and discussions about preferences for care if a person becomes demented—might still gain some support.

Conclusion

In this chapter, we have looked at various ethical issues involved with the care of people, and tried to look beyond Western constructs, with an emphasis on South Asia. There is a major debate in ethics about the role for Western ethical thought in other cultures, and there seems to be both rooms for some Western ethical concepts and a place for non-Western ideas of ethics.

One of the major differences between ethics in the West and elsewhere is that different topics have prominence in different places.

The question of whether the future is best left to fate or God is a good example of this—it is not something that usually enters Western discussions of end-of-life care but may be a major underlying issue in non-Western discussions.

Another area that is different in emphasis between non-Western countries and Western countries is the stigmatization of dementia by including it as a ‘mental illness’. Whereas, in many developing world countries, dementia is stigmatized by its association with mental illness, in the West, dementia, like other disorders with an organic basis (including epilepsy, developmental disability and, more recently, substance abuse), has been distinguished from ‘mental illness’. Laws in countries like Australia make distinctions between an ‘incapable person’ (through ‘mental infirmity’) and a ‘mentally ill person’. The ‘mentally ill’ person requires care, treatment or control for his own good or the public interest, whereas the mentally infirm person is only incapable of managing his own affairs and not in need of treatment or control [18]. Guardianship, originally intended for the protection of the affairs of minors, has become the standard approach for managing the affairs of people with dementia, while mental health legislation—with its greater emphasis upon control—is used for those with other mental illnesses.

In Australia, organizations such as Alzheimer's Australia appear to have been successful in decreasing the stigmatization of dementia, in part through severing its link in the public mind with mental illness. While it can be argued that this sort of redefinition does nothing to affect the main problem of the underlying stigmatization of mental illness, in countries like Australia, dementia, now freed from its links with mental illness, gets increased public visibility and support, and those with dementia are treated more with sympathy than with fear.

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