Chisholm Health Ethics Bulletin

Drawing on thorough research, the best of human insight and the strengths of Catholic teaching, we offer an ethical vision to inform modern health care. We strive to guide our readers to greater knowledge and deeper understanding about issues in health care, and to assist all people in their search for insight and wisdom.

In this issue

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Welcome to the *Chisholm Health Ethics Bulletin*. Every year, the Centre holds a one-day conference on a significant topic related to health and aged care. I am pleased to announce that our 2016 conference will address 'The Challenges of Dementia.' It will be held on Wednesday 14 September at the Catholic Leadership Centre in East Melbourne. I will keep you informed as plans for our conference are finalised. For now, you might like to mark the date in your diary.

My article in this Bulletin is part of the Centre's preparation for this conference. It is an overview of the significant challenges which dementia poses. Over the next three decades, both within Australia and around the world, the number of people living with dementia will almost triple. It will neither be practical nor even desirable to accommodate everyone with dementia in residential aged care. Instead, many persons with dementia–particularly in the early stages of their condition–will continue to live in the community. So that they can enjoy the best possible quality of life, it is essential that we create dementia-friendly communities. I believe too that, along with many other groups in our society, the Catholic Church has a vital role to play both in the care of persons living with dementia, and in the creation of dementia-friendly communities.

The second article in this Bulletin is by Centre researcher Emanuel Nicolas Cortes Simonet. One of the great books written in recent years is Atul Gawande's *Being Mortal*. Nicolas has written a thoughtful review of this book. When people age, or become terminally ill, or particularly as the end of their life approaches, honest discussions with their health professionals and their carers, families and friends are very important. Without these discussions, we cannot know a patient's priorities. And without knowledge of a patient's priorities, we cannot deliver appropriate care to them. Both Gawande's book and Nicolas's article call on health professionals to facilitate in-depth communication with their patients about what really matters, particularly as the end of life approaches.

The third article in this Bulletin is by Centre researcher Sr Carol Ong RSM. It is about the important topic of moral distress. Moral distress is the feeling or state of distress which we can experience when we are unable to do what we believe to be morally right. It is increasingly being recognised as a significant issue for health professionals. Repeated experiences of moral distress can make us more susceptible to moral distress, and can also make our distress much more severe. As strategies to prevent or minimise moral distress, Sr Carol proposes open and clear communication, respect, inclusivity, openness to differences, compassion, support, education, and the capacity to grow in self-awareness.

Kevin McGovern ✠

About the Caroline Chisholm Centre for Health Ethics

The Caroline Chisholm Centre for Health Ethics is a Catholic bioethics centre:

• We research and publish about health care issues.

• We provide education and training about health ethics to health professionals and the general community.

• Over the phone or face to face, we assist without discrimination any person who seeks help in making decisions about health care.

• We contribute to community discussion and debate by making public comments about important matters related to health care.

• We also assist health care institutions in the development of policies, protocols and procedures, particularly in areas which might be ethically contentious.

Catholic bioethics is based upon both faith and reason. "Faith and reason," Pope John Paul II once wrote, "are like two wings on which the human spirit rises to the contemplation of truth." (John Paul II, *Fides et Ratio*) Thus, the long Catholic tradition contains much reasoned reflection on human experience – reflection which has discerned a natural ethic which is sometimes called the natural law. However, the Catholic tradition also contains much reflection on the wisdom which is found in what the Church recognises as divine revelation. This includes the Bible and above all the example of Jesus Christ. Noting that Jesus healed the sick, for example, many Catholic health and aged care services proudly proclaim that they are continuing the healing mission of Jesus.

Above all, faith and reason reveal the inherent dignity of each and every human being, no matter how sick, aged, frail or disabled we may be. In the Bible, the book of Genesis records that God created human beings "in the image of God." (Gen 1:27) In the Catholic tradition, it is this *imago Dei* – the image of God which is present in every human being – which is the ultimate foundation of human dignity.

From this starting point, Catholic bioethics contributes to moral discourse in every stage of the life continuum from conception to natural death. This Catholic perspective strives to be holistic and to take into consideration all the needs of the individual – physical, emotional, psychological, social, and spiritual. The Catholic approach to care is marked by great emphasis on the importance of pastoral and spiritual care.

Catholic bioethics makes a significant contribution to the moral debates in our society that are critical in this age of advancing technology. It reminds us of our meaning and purpose in life, and guides us towards its fulfilment, not just as individuals but as people in community.

The Challenge of Dementia

Over the next three decades, the number of people living with dementia both in Australia and around the world will almost triple. This calls for significant changes within our society. It calls for international cooperation, with particular assistance being given to low income countries. It calls for increased research into many aspects of dementia, ranging from the search for a cure to the identification of best practice in the care of persons with dementia. It calls for upskilling in Australia's health, community and aged care sectors. Because many people with dementia will continue to live in the community, above all it calls for the creation of dementia-friendly communities.

Let me begin this article with a story which makes an important point. Shortly after Vince O'Rourke retired, his wife Margaret was diagnosed with younger onset dementia. Both Vince and Margaret were committed Catholics, and one day early in her illness Margaret said, "'I wish I were a leper.' Startled, [Vince] asked why a leper. She said, 'If I were a leper, He would cure me.'"[1]

In his memoir of caring for Margaret until her death seven years later, Vince develops this image. Their experience, he notes, was "that many friends and even extended family members could not deal with the outward expressions seen in the one having the disease." As a result, many people did not keep in contact, and Vince and his wife "felt abandoned, outcasts like the lepers of old." Vince therefore likens "the stigma society places on those who suffer from Alzheimer's to that of the leper in Biblical times."[2]

People living with dementia clearly suffer because of their disease. However, they also suffer because of what Vince O'Rourke calls the leprosy of dementia: the stigmatisation, stereotyping, discrimination, social exclusion and social isolation which so many people with dementia currently experience in our society. At this time, we cannot cure dementia. But if we all work together to create dementia-friendly communities, we *can* cure the leprosy of dementia. This article will say a number of things about dementia, and note many other things which we should also be doing as we respond to the challenges of dementia. Let me begin, however, by highlighting what I consider perhaps our most important challenge: overcoming the leprosy of dementia by creating dementia-friendly communities. I am also convinced that, along with many other groups in our society, the Catholic Church with its parishes, its community and aged care services, its hospitals, its social service agencies, and its schools has a vital role to play in what must be a significant social change.

This article follows a common pattern in Catholic social thought which is usually referred to as See, Judge and Act.[3] Thus, the first section of this article looks at the reality of dementia. It explains what dementia is. It notes that as the population ages, we can expect many more people to be affected by dementia. And it offers several stories which reveal something of the impact which dementia has. What we ultimately make of all this, however, depends very much on the ethical perspective from which we consider dementia.

Thus, the second section of this article puts forward an appropriate ethical framework, taking this from *Dementia: Ethical Issues* by the UK Nuffield Council on Bioethics. In the light of all this, the final section of this article considers what we should do. It explores what should be done internationally, in Australian society, in Australian health, community and aged care, and in research.

1. SEE

What is dementia?

Dementia is not a disease itself, but rather the term used to describe the symptoms of a large group of diseases which cause a progressive decline in a person's mental functioning. These symptoms include losses in memory, language, comprehension, thinking, judgement, emotional control, sociability, and the control of bodily functions. They are caused by physical changes in the brain which lead to chronic, progressive deterioration of the nerve cells. Because the brain continues to deteriorate, dementia is ultimately a terminal and fatal condition.[4]

There is no cure for most forms of dementia. In some cases, there are medications which can reduce symptoms. However, they do not stop the underlying progress of the disease.[5]

There are more than 100 different diseases which cause dementia. Alzheimer's disease is the most common of these, and it is responsible for 50 to 75% of dementia cases in Australia. Vascular dementia is the second most common, and it causes 20 to 30% of Australian dementia cases. Other forms include dementia with Lewy bodies, fronto-temporal dementia, Parkinson's disease dementia, Pick's disease, and alcohol-related dementia. The prevalence of dementia increases as we age. However, it should be stressed that dementia is not a natural part of ageing, and the development of dementia is not inevitable as we grow older. Younger onset dementia is any form of dementia diagnosed in a person under the age of 65.[6] In different diseases, the symptoms of dementia may appear differently and in a different order.[7] This is why an accurate diagnosis is important, and why the person themselves and everyone involved in their care should know the symptoms typically associated with their particular disease.

Amongst the symptoms of dementia, some are particularly concerning. These symptoms can significantly decrease the quality of life of the person with dementia. They can add significantly to the burden of caregivers—whether these are informal carers such as family members, or formal carers such as the staff in residential aged care. They can also lead to the premature institutionalisation of the person with dementia. These intrusive and difficult symptoms are known as the Behavioural and Psychological Symptoms of Dementia (BPSD). They include behavioural symptoms such as physical aggression, screaming and cursing, agitation, shadowing and repetitive questioning, pacing and wandering, and sexual disinhibition. They also include psychological symptoms such as anxiety, depression, sleeplessness, delusions, and hallucinations. Thankfully, BPSD can often be managed quite well. Strategies include non-pharmacological interventions such as identifying and eliminating the trigger for the behaviour, recreational and music therapy to reduce anxiety and agitation, and so on. They also include pharmacological

interventions such as antidepressants, and antipsychotics to treat physical aggression, hallucinations and delusions.[8]

The increasing incidence of dementia

Over the next few decades, the number of older persons will rise sharply, both in Australia and worldwide. We can therefore expect a significant increase in the number of persons with dementia.

The authoritative resource on incidence worldwide is the *World Alzheimer Report 2015* from Alzheimer's Disease International.[9] Based on the best available evidence, the report reaches the following conclusions:

- In 2015, 46.8 million people worldwide lived with dementia. Of these, 58% were in low and middle income countries.
- In 2030, this will increase to 74.7 million. Of these, 63% will be in low and middle income countries.
- In 2050, this will increase again to 131.5 million. Of these, 68% will be in low and middle income countries.
- The number of people living with dementia is currently almost doubling every 20 years.
- Between 2015 and 2050, the number of people living with dementia in high income countries will increase by 116%. In the same period, the number of people living with dementia in low income countries will increase by 264%.[10]

Clearly, caring for these greatly increased numbers of persons with dementia will be a great challenge worldwide. It will be an even greater challenge in low income countries. We must therefore recognise now that dementia is an international health policy priority. Planning to respond to this growing challenge cannot be postponed.

A similar trend is expected in Australia. The authoritative resource here is *Dementia in Australia*, issued by the Australian Institute of Health and Welfare on 27 September 2012. It provides the following figures:

- In 2011, about 298,000 Australians were living with dementia.
- In 2015, about 342,800 Australians were living with dementia.
- In 2030, about 550,200 Australians will be living with dementia.
- In 2050, about 891,400 Australians will be living with dementia. This is almost triple the 2011 figure.[11]

Dementia is now the second leading cause of death in Australia. In 2013, 10,993 Australians died because of dementia.[12]

In the light of these figures, it is entirely appropriate that all Australia's Commonwealth, State and Territory Health Ministers agreed in August 2012 to designate dementia as a National Health Priority Area.[13] It is also entirely appropriate that—once again with the agreement of all Australia's Health Ministers—our *National Framework for Action on Dementia 2015–2019* was issued in September 2015.[14] It should also be clear that it would neither be desirable nor perhaps even possible to accommodate all these persons with dementia in residential aged care. Instead, many more—particularly in the early stages of the disease—will continue to live in the community. This is yet another reason why the creation of dementia-friendly communities is so important.

Stories of dementia

The medical information and epidemiological data above give us some understanding of dementia. To understand dementia fully, however, we must connect with narratives about the experience of dementia. The best way to do this, of course, is to be part of a real-life dementia journey. Whether we are afflicted by dementia ourselves, the family carer of a person with dementia, or simply one of many friends who offer support and help in whatever way we can, in this way we experience very powerfully the joys and the hopes, the grief and the anxieties[15] of a dementia journey. On the other hand, if this is not possible, stories of dementia can also guide us. Here are some:

There are at least two very significant movies about dementia. The first of these is *The Notebook* from 2004. It is a poignant story of how love endures in difficult circumstances after a diagnosis of dementia. 'Sundowning' is a state of confusion, agitation and even aggression which people with dementia can experience as the day ends. There is a very realistic (and upsetting) portrayal of sundowning in this movie. Some people who care for a spouse with dementia say that they cannot watch this movie as it is all too real for them. Another powerful movie about dementia is *Still Alice* from 2014. It is a story about younger onset dementia. Its main character is a professor of linguistics, which means that the dementia is tragically taking from her knowledge and skills which she has spent a lifetime acquiring. This movie also illustrates the sometimes heavy demands which family members can face as they strive to care for a person with younger onset dementia.

Let us turn to two books which tell the story of dementia from the perspective of family members caring for a person living with dementia. In *Remember Me, Mrs V?*,[16] Tom Valenta writes about his wife Marie who had younger onset Alzheimer's disease. He also tells the stories of thirteen other people with various forms of dementia. The final chapter is ten hints for surviving as a carer. In my view, however, one of the most moving and revealing stories of a dementia journey is Vince O'Rourke's memoir of caring for his wife Margaret over seven years. Vince had kept a diary, which means that in just over 200 pages he is able to record so much of the day-to-day life of caring for someone with dementia. Some of the memories are very sad. A few years after her diagnosis, Margaret's attempts at conversation became impossible to follow. Very soon, she had no memory of their life together. She also did not recognise Vince, nor know that he was her husband. There are very frequent entries about Vince's sleep deprivation, and the ongoing challenges of urinary and faecal incontinence. Eventually, Margaret no longer recognised her reflection, and therefore found a new friend in her reflection in the mirror.[17] Other memories are more consoling. Even after she lost the ability to speak, Margaret retained her beaming smile of recognition. Margaret's kind hairdresser Mary was not distressed when Margaret had an animated conversation with the people in the mirror. And the kind people at Mass were not distressed when Margaret spoke loud nonsense to Vince during the service.[18] To read Vince's book is to gain a touching and comprehensive insight into the challenges and joys of caring for someone who is living with dementia.

Christine Bryden is a survivor of dementia who is an author, speaker and dementia advocate. In 1995, at the age of 46, she was diagnosed with younger onset dementia. Her survival defies medical expectations as her dementia has progressed more slowly than is usual. Christine has spoken about dementia at conferences around the world. She is passionate about overcoming the stigma of dementia, and creating dementia-friendly communities. She has written four books. Her first book *Who will I be when I die?* (1998) records her experiences in the three years after her diagnosis as she gradually lost the ability to undertake various tasks. Her second book *Dancing with Dementia* (2005) recounts her ongoing journey of living positively with dementia. Her third book *Before I Forget* (2015) is her life story from birth to the present. And her fourth book *Nothing About Us, Without Us* (2015) is a selection of her talks. Her honest "insider's perspective" on dementia gives us a valuable insight of what it is like to live with dementia.[19]

2. JUDGE

The first section of this article has given us an outline of what dementia is. The condition of dementia itself raises many ethical questions. For example, given the diminishments which dementia brings, does the person with dementia remain a human person with human rights? At the same time, the treatment and care of persons with dementia also raise ethical questions. For example, if a person with dementia is agitated and upset, is it right simply to distract them or even to lie to them? Because of these questions, our next step must be to identify an appropriate ethical framework–a framework which will guide us as we respond to the person with dementia and to their various needs.

In my opinion, one of the best commentaries on the ethical issues associated with dementia was issued in the United Kingdom in October 2009 by the Nuffield Council on Bioethics. It is just over 200 pages. The Council also issued a 17-page Executive Summary, a 20-page Short Guide in large print, and a 2-page summary of the report's Key Recommendations.[20] When the report was discussed by the British House of Lords on 2 December 2009, Baroness Thornton on behalf of the UK Government welcomed "the excellent report by the Nuffield Council," and stated that "the Government are taking this report very seriously indeed."[21] An editorial in *The Lancet* described it as a "thoughtful, valuable contribution."[22] Alzheimer's Australia recognised the importance of the report by bringing one of its authors, old age psychiatrist Professor Julian C. Hughes, to Australia for a national lecture tour. From 15 to 24 June 2010, Professor Hughes spoke about the Nuffield report in Canberra and in the capital city of every Australian state.[23]

In its 200 pages, the Nuffield report provides a detailed and well-balanced analysis of just about every ethical issue associated with dementia. We will not explore all those insights here. However, we will do two things. We will set out the ethical framework which informs their approach to dementia. And here and there we will note important conclusions and implications which follow from this framework. The Nuffield ethical framework for considering issues related to dementia has six components.[24]

The first of these is a case-based approach to ethical decisions. The Nuffield Council recognises that caring for a person with dementia raises many ethical questions, and that both family and professional carers need support as they seek to answer these questions. What is more, in all these quandaries, the best approach is not to seek to apply some grand ethical theory, but instead to consider all the circumstances of a specific situation, to identify circumstances which are highly relevant, and then in the light of all this to come to a reasonable conclusion. For example, when she is cooking dinner, should an elderly woman lock her husband who has dementia out of the kitchen? Perhaps she should do so if there was a serious risk that he might burn himself on the hot stove. Or perhaps she should not do so if being locked out upset him, and he remained upset for a long time afterwards.

The second component of the Nuffield ethical framework is a belief about the nature of dementia. Dementia arises as a result of a brain disorder. It causes harm to those who have it. This is the fundamental reality of dementia. Recognising this reality should shape our response to dementia, both as individuals and as a society.

The third component is a belief about quality of life with dementia. Because this is important, it is worthwhile to quote the experts on dementia who prepared the Nuffield report. They state, "With good care and support, people with dementia can expect to have a good quality of life throughout the course of their illness."[25] Because dementia causes harm, this quality of life will not be as good as it was before the person developed dementia. Even so, as the Council has stated, with appropriate care, a person with dementia should expect to enjoy a good quality of life, and they should expect this not just in the immediate future but throughout the course of their illness. This has two important implications. Firstly, it means that we should respectfully challenge those who hold the view that people with dementia would be better off dead. (For example, after we had visited a person with dementia, I vividly remember one man who said, "If I ever get like that, shoot me!") Dementia causes great fear in many people. Cancer once caused the same fear, though less so nowadays.[26] We need to reassure those who now fear dementia in this way. With dementia, we might say, life is certainly changed. But even with dementia, we must affirm that life is not ended. After a diagnosis of dementia–after having time to work through a variety of painful emotions–we should still look to the future with hope. We can and should expect a good quality of life throughout the course of our dementia journey. The second implication here is about care. Given that people with dementia can enjoy a good quality of life with appropriate care, as a society we must ensure that this care is provided.

The fourth component of this ethical framework is that our ethical decision-making should consider not only the interests of the person with dementia but also the interests of their family and professional carers. There are at least two reasons for this. The first is that these carers are persons in their own right, whose interests therefore merit consideration. The second is that carers will be more able to continue to care for persons with dementia if their own interests are also attended to. Because of these considerations, some things sometimes happen for persons with dementia which would not be their first preference. For example, even though they might not like respite care, a person with dementia might have to go into care for a while so their family carer can have a much-needed rest.

The fifth component is solidarity. Solidarity is the commitment which we should have to one another and to the common good. It is a commitment which we should have particularly to those who for various reasons cannot really look after themselves. If we were disabled, we would hope that we would be provided with the care we would need. Turning this around, solidarity makes some claim on us as individuals, as family members, and as members of society. Solidarity requires that our society provides for its members who develop dementia, and also that that we support the family and professional carers who care for them.

The final component of this ethical framework is about recognising personhood, identity and value. Like the third component of the framework, this too is most important. Let us therefore once again quote the experts on dementia who prepared the Nuffield report. They state, "The person with dementia remains the same, equally valued, person throughout the course of their illness, regardless of the extent of the changes in their cognitive and other functions."[27] This has two important implications. Firstly, there are some people who effectively deny the personhood of someone living with dementia. For example, they might say, "Really, my mother died two years ago. All that's left now is a shell." Or they might say that "the lights are on but nobody's home." Or again, they might describe dementia as a "living death," or "death that leaves the body behind." Perhaps we have tended to hold views like these ourselves. Or perhaps we know another person who holds such views. Either way, the first implication here is that we should respectfully correct these mistaken views. Even though I am very different now from how I was when I was a child, philosophically I am still the same person. In the same way, someone living with dementia has also changed. They have become disabled–and perhaps even profoundly disabled. In all this, however, they have not ceased to be a person. Instead, they have simply become a disabled person–a person with disability. Indeed, philosophically, they remain the same person they have always been. (Two signs of this are their enduring bodily identity and their enduring social connections.) What is more, because they are a person– because they are a human being–they are of inestimable value, and they should always be treated with dignity and respect.[28] When a loved one is affected by dementia– especially when they are profoundly affected–we undergo a painful ordeal of grieving. We mourn the changes in the one we love, and all the things that they can no longer do and enjoy. We mourn the changes in our own relationship with them, and all the things that we can no longer do and enjoy together. Perhaps we particularly mourn the support that they can no longer give us. We also mourn so many other things–the next generation who will not know an aged relative in his or her full vitality, lost opportunities to speak with them about the things that really matter, perhaps (if we are honest) the demands that their care sometimes makes upon us. It is important, however, that we do not allow all this grieving to blind us to the central truth that despite their disabilities our loved one remains the same, valued person whom they have always been. And at other times, we may need to respectfully remind another person of this same truth. The second implication here is about care. Given that people with dementia remain the same, valued persons they have always been, it is important that society recognises this by providing them with appropriate care.

In the first section of this article, we looked at the reality of dementia. In this second section, we have identified a robust ethical framework–a framework which can guide us as we make sense of the phenomenon of dementia, and as we seek to answer the many ethical questions which it raises. These two reflections lead us into the third section of this article, where we consider what we should do as we respond to the challenge of dementia.

3. ACT

What should we do? This section explores four important areas where action is needed. These are: (i) an international response, (ii) within Australian society, (iii) in Australian health, community and aged care, and (iv) in research. In each discussion, where appropriate, I will note the contribution which should be made by the Catholic Church and its agencies.

An international response

As we have already noted, over the next few decades, with an ageing population the number of people living with dementia is expected to almost triple, both within Australia and across the world. What is more, the greatest increase will be in low and middle income countries. This situation calls for a truly international response.

One element of this response is the development of national dementia plans in every country. The OECD (Organisation for Economic Co-operation and Development) has identified 10 key objectives which should be addressed in these plans.[29] As we have noted, Australia has such a plan.[30] In November 2015, this made us one of 21 countries with a national dementia plan, while another 9 countries had a plan in development.[31] Given that there are just under 200 countries in the world, there is still quite a long way to go.

Another vital issue is international cooperation in action against dementia. Dementia has been on the agenda of the G8 (now the G7) since December 2013. This and other international initiatives led recently to the World Health Organization's *First Ministerial Conference on Global Action Against Dementia* in Geneva on 16–17 March 2015. Along with senior representatives of several Intergovernmental Organisations, many Non-Governmental Organisations (NGOs), and many highly regarded Foundations and Academic Institutions, senior representatives of 89 countries attended. Together, they produced a *Call for Action* which calls (among other things) for "raising the priority accorded to global efforts to tackle dementia," and "strengthening international efforts to support plans and policies at all levels for people living with dementia, particularly in low- and middle-income countries."[32]

In all this, a good start has been made. In the years ahead, more countries will produce dementia plans, and international cooperation will continue to develop. Because of the increasing need in low-income countries, dementia will probably move onto the agenda of overseas aid agencies. This could affect the priorities of Australia's overseas aid, along with the work of Catholic agencies such as Caritas Australia and Catholic Mission.

Australian Society

I have already stated that one of our key challenges is the creation of dementia-friendly communities. We have already noted the dramatic increase expected over the next three

decades of people living with dementia. We have also noted that many of these–particularly in the early stages of the disease–will continue to live in the community. To assist people in these circumstances to enjoy the highest possible quality of life, the creation of dementia-friendly communities is essential.

Two or three decades ago, Australian society typically excluded people with physical disabilities. Since then, a quiet revolution has taken place. Now, there are access ramps for people with wheelchairs, hearing loops for hearing-impaired people, and tactile paving on street corners for people who are visually handicapped. These and many other changes have assisted people with physical disabilities to participate in society more easily and more fully. Our next challenge is to initiate other changes so that people with dementia and other cognitive disabilities are also assisted to participate in society.

Creating dementia-friendly communities involves a number of inter-related steps. One is overcoming fear and stigma. Another is helping people understand what dementia really is. Yet another step is giving people guidance and training in communicating effectively with people who are living with dementia. Still another step is ensuring that the physical environment is easy to navigate and safe for people with dementia. And one more step is offering people with dementia opportunities for employment, volunteering and study.

To assist us in all of this, Alzheimer's Australia has produced a number of very useful resources and training opportunities. There are resources for communities, elected community representatives, and businesses.[33] There is an excellent, short brochure *Talk to Me* which offers "good communication tips for talking to people with dementia."[34] There is an online training resource *Is it Dementia* which in 15 minutes or so educates employees in various industries about the signs of dementia and skills for communicating effectively with a person with dementia.[35] There are many other resources and training opportunities as well.

I am convinced that the Catholic Church and its agencies should play a significant role in the creation of dementia-friendly communities in Australia. While Catholic agencies should make a very valuable contribution, this is a particular challenge to Catholic parishes and churches. This challenge is to create dementia-friendly churches all around Australia. What is more, this is a challenge which the Catholic Church really should not ignore, for the promotion and protection of human dignity is core business for the church.

In the 2011 Australian Census, 25.3% of the Australian population identified as Catholic. This was 5.4 million of what was then the total Australian population of 21.5 million.[36] What is more, according to the 2011 National Count of Attendance, about 12.2% of the Catholic population attend Catholic Mass on a typical weekend. This is just over 662,000 people.[37] Let me stress the significance of these figures. On any typical weekend, in Catholic churches all around Australia, just over 3% of the Australian population attends Catholic Mass. If the Catholic Church can create dementia-friendly churches, this will make a significant contribution to the development of dementia-friendly communities all around Australia.

An excellent resource has been prepared to assist Catholic parishes and churches to become dementia-friendly. This is *Ministering to People with Dementia: A pastoral guide*, issued by Catholic Health Australia in 2008. It is just over 50 pages. It was prepared with the support and active involvement of Alzheimer's Australia. In its Foreword, the then-President of the Australian Catholic Bishops Conference Archbishop Philip Wilson wrote, "I commend all priests and parishes in Australia to make constant reference to this timely publication." There are chapters on what dementia is, on communicating to a person with dementia, on supporting their spiritual journey and ministering to them, and on ministering to carers. The publication quotes Christine Bryden, who says to priests and church personnel, "You play a vital role in relating to the soul within me, connecting at this eternal level. Sing alongside me, touch me, pray with me, reassure me of your presence and through you of Christ's presence."[38]

Australian health, community and aged care

Australia's health, community and aged care sectors are rightly upskilling so that they can care more effectively for people with dementia. The Australian *National Framework for Action on Dementia* highlights the need for timely diagnosis of dementia, and the role of general practitioners (and nurse practitioners in rural and remote Australia) in providing primary care and in directing persons with dementia to specialist services.[39] The community care sector recognises that they support many family carers who are looking after a loved one with dementia. In home care, it is important to maintain adequate levels of community engagement. This requires an enablement approach which focusses not on what the person with dementia cannot do, but instead on what they can do.[40] Australia's hospitals are aware that a significant number of their patients live with dementia: they are therefore involved in continuous quality improvement to enhance their care of persons with dementia.[41] Australian residential aged care recognises that the care of persons with dementia is part of their core business. In 2013–14, more than 50% of aged care residents in Australia had a diagnosis of dementia.[42]

In this endeavour to provide appropriate care for persons with dementia, at least three resources should be highlighted:

The first is the Alzheimer's Australia *National Dementia Helpline*, which is 1800 100 500. This telephone information and support service is for people with dementia, their carers, families and friends, and anyone who is concerned about memory loss. It can also be used by health professionals, service providers, community organisations and students.[43]

Another resource is the Dementia Behavioural Management Advisory Services (DBMAS). Funded by the Australian Government, this is a free service to ease the burden for formal and informal carers. Family carers, aged care workers, and hospital staff can contact the service at any time of the night or day on 1800 699 799. The service will provide advice and support to ensure that the best possible care is being offered to a person with dementia.[44]

In some cases, DBMAS will refer to the third resource, the Severe Behaviour Response Teams (SBRTs). These teams assist staff in residential aged care homes. They are called in when residents are exhibiting very severe Behavioural and

Psychological Symptoms of Dementia (BPSD) which are posing a significant risk either to themselves or to others. SBRTs operate 7 days a week from 7 am to 7 pm. Within those times, they will respond within 4 hours to assess and triage each situation. Within 48 hours, they will hold either a face-to-face or telehealth case conference to develop immediate and longer term care plans.[45]

In Australia, the Catholic health, community, and aged care sector provides about 9,000 hospital beds, 8,000 Community Aged Care packages, and 19,000 residential aged care beds. It is the largest non-government provider of health, community, and aged care services in Australia, providing approximately 10% of Australia's health care services.[46] The Catholic sector already plays its part in the provision of services to people with dementia, and it will continue to do so. In this, it will be guided by one of its core values: solidarity in the mystery of suffering and death. Our *Code of Ethical Standards* states that "Catholic health and aged care services should be marked by a material and spiritual solidarity with people who are sick, disabled, frail, elderly or dying."[47] This commits the Catholic sector to a particular concern for people living with dementia.

Research

Over the past decade, there has been a global recognition that research into dementia has been grossly underfunded. Given the widespread prevalence of dementia and its serious consequences, it is now an urgent global priority to increase capacity and funding for dementia research.[48] This research must explore a number of areas. There must be basic science research to understand the mechanisms whereby dementia develops. There must be research to improve the prevention, diagnosis, and treatment of dementia. There must be research into best practice in the care of persons with dementia. There must be social science research into the human impacts of dementia, including stigma, and how people can best be supported to live well with dementia. There must also be translational research to bring new findings rapidly into policy and practice. None of these areas should be neglected. For example, finding a cure for one or more of the diseases which cause dementia is obviously an attractive goal. Even so, we must still care for many people who live with dementia, and research is therefore also needed to identify best practice for that care.

Australia has a number of centres and institutions which specialise in dementia research. These include the three Dementia Collaborative Research Centres. Established in 2006, these centres focus on early diagnosis and prevention, assessment and better care, and carers and consumers.[49] They also include the Partnership Centre for Dealing with Cognitive and Related Functional Decline in Older People, the Clem Jones Centre for Ageing Dementia Research, the Alzheimer's Australia Dementia Research Foundation, the Hazel Hawke Alzheimer's Research and Care Fund, and many more.[50]

Heeding the global call for increased research into dementia, the Australian Government in its 2014 Budget provided an additional $200 million over 5 years to boost dementia research in Australia. This included $50 million to establish at the National Health and Medical Research Council a new National Institute for Dementia Research. This Institute was established on 7 August 2015. It will identify dementia research priorities for Australia, and disburse funds for dementia research. With additional funding from the National Health and Medical Research Council and the Australian Research Council, by October 2015 it had already disbursed over $78 million for dementia research.[51]

The Catholic health, community and aged care sector, along with Australian Catholic University and the (Catholic) University of Notre Dame Australia, are already involved in much medical research. This includes research into various aspects of dementia and dementia care. As Australia's dementia research is boosted, Catholic institutions will be ready to contribute.

Conclusion

This article has demonstrated that the increasing prevalence of dementia over the next three decades poses significant challenges. It has also demonstrated that in many areas a good start has already been made to address needs both now and in the future. As that future unfolds, let each of us be ready to play our part in addressing the challenges of dementia.

ENDNOTES

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[3] See, for example, John XXIII, *Mater et Magistra (Christianity and Social Progress)*, #236, Holy See, http://w2.vatican.va/content/john-xxiii/en/ encyclicals/documents/hf_j-xxiii_enc_15051961_mater.html; and Paul VI, *Octogesima Adveniens (A Call to Action)*, #4, Holy See, http://w2.vatican.va /content/paul-vi/en/apost_letters/documents/hf_p-vi_apl_19710514 _octogesima-adveniens.html.

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[5] For more on this and on the search for potential treatments, see Alzheimer's Australia (AA), "Research into Dementia Treatments and Cure," AA, https://fightdementia.org.au/research-publications/research/areas-of-dementia-research/research-into-dementia-treatments-and-cure.

[6] *National Framework*, 4–5.

[7] Nuffield Council on Bioethics (NCB), *Dementia: Ethical Issues*, 5–6, 8–10, NCB, http://nuffieldbioethics.org/project/dementia/.

[8] For more on BPSD, see International Psychogeriatric Association, *Behavioral and Psychological Symptoms of Dementia (BPSD) Educational Pack*, Dementia Behaviour Management Advisory Service, http://dbmas.org.au/Uploads/ resources/IPA_BPSD_Educational_Pack.pdf.

[9] Alzheimer's Disease International (ADI), *World Alzheimer Report 2015: The Global Impact of Dementia – An Analysis of Prevalence, Incidence, Costs and Trends*, ADI, http://www.alz.co.uk/research/WorldAlzheimerReport2015.pdf. This report was issued on 25 August 2015. It is interesting to note that on the day before this, the Chair of Alzheimer's Disease International Glenn Rees AM spoke about dementia at the Catholic Health Australia National Conference.

[10] Ibid., 1. I first gave a public presentation on the challenge of dementia on 11 July 2012 at an in-service for the clergy of the Catholic Diocese of Wollongong. (By a coincidence, it was on the same day and around the same time that the then-National President of Alzheimer's Australia Ita Buttrose AO OBE was also speaking about dementia at the National Press Club.) Then, the authoritative resource on incidence worldwide was *Dementia: A Public Health Priority*, issued in April 2012 jointly by Alzheimer's Disease International and the World Health Organization (WHO). It is sobering to note that the extra information gathered since then has led to an increase in the predictions about dementia of about 14%. In 2012, the 2030 estimate was 65.7 million worldwide living with dementia. It is now 74.7 million. Similarly, in 2012, the 2050 estimate was 115.4 million. It is now 131.5 million – an increase of just over 16 million. For the 2012 report, see WHO,

http://www.who.int/mental_health/publications/dementia_report_2012/en/index.html.

[11] Australian Institute of Health and Welfare (AIHW), Australian Government, *Dementia in Australia*, 2012, 156, AIHW, http://www.aihw.gov.au/WorkArea/DownloadAsset.aspx?id=10737422943. These figures probably do not need significant revision. As noted on page 13 of the AIHW report, they were based on dementia prevalence rates for the Australasian region given by Alzheimer's Disease International in their *World Alzheimer Report 2009*. Interestingly, after all its new calculations, the *World Alzheimer Report 2015* comes to exactly the same dementia prevalence rate for the Australasian region. This is perhaps why the figures from the 2012 AIHW report were used without change in Australia's 2015 *National Framework for Action on Dementia 2015–2019*. Note, however, that some studies have provided epidemiological evidence of a reduction in dementia rates, probably because of a reduction in such risk factors as smoking and vascular disease, and an increase in protective factors such as better education and a healthier and more active lifestyle. For more on this, see Perminder S. Sachdev, "Is the incidence of dementia declining?: A Report for Alzheimer's Australia," April 2014, Alzheimer's Australia, https://fightdementia.org.au/sites/default/files/Paper_39_Is_the_incidence_of_dementia_declining.pdf; Yu-Tzu Wu et al., "Dementia in western Europe: epidemiological evidence and implications for policy making," *The Lancet Neurology* 15, no. 1 (January 2016): 116–124.

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[14] The publication details of this framework can be found in endnote 4.

[15] cf Vatican Council II, *Gaudium et Spes*, Pastoral Constitution on the Church in the Modern World, n. 1, 7 December 1965, Holy See, http://www.vatican.va/archive/hist_councils/ii_vatican_council/documents/vat-ii_const_19651207_gaudium-et-spes_en.html.

[16] Tom Valenta, *Remember Me, Mrs V?* (Melbourne: Michelle Anderson Publishing, 2007). [17] *I Wish I Were A Leper*, 36, 50–53, 55–56, 93, 139, 67.

[18] Ibid., 73, 96, 157.

[19] For more on Christine Bryden, see "Christine Now," *Christine Bryden*, http://www.christinebryden.com/about-christine/; and "About Christine," *Christine Bryden*, http://www.christinebryden.com/about-christine/. Christine's book are *Who will I be when I die?* (London: Jessica Kingsley, 2012); *Dancing with Dementia: My story of living positively with dementia* (London: Jessica Kingsley, 2005); *Before I Forget: How I survived being diagnosed with younger-onset dementia* (Docklands, VIC: Penguin, 2015); *Nothing About Us, Without Us: 20 years of dementia advocacy* (London: Jessica Kingsley, 2016).

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[21] See United Kingdom Parliament, http://www.publications.parliament.uk/pa/ld200910/ldhansrd/text/91202-0001.htm.

[22] "Dealing with the ethical dimension of dementia care," *The Lancet* 374, no. 9696 (3–9 October 2009): 1120.

[23] I heard Professor Hughes speak in Melbourne on 15 June 2010.

[24] Nuffield Council on Bioethics, xvii–xviii, 19–33.

[25] Ibid., xviii, 21.

[26] cf ibid., 58–59.

[27] Ibid., xviii, 21.

[28] For more on this, see ibid., 30–33.

[29] Organisation for Economic Co-operation and Development (OECD), *Quality Indicators for Dementia*, OECD, http://www.oecd.org/els/health-systems/Item-4c-HCQI-dementia-OECD.pdf.

[30] The current version of this is Australia's *National Framework for Action on Dementia 2015–2019*. Its publication details can be found in endnote 4.

[31] Glenn Rees, *Global Progress, Local Action, Development of a National Dementia Care Policy*, Alzheimer's Disease International, https://www.alz.co.uk/sites/default/files/pdfs/glenn-rees-global%20progress-local-action-asia-pacific-regional-conference-slides.pdf.

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[33] All these resources and more are available at *Dementia-Friendly Communities*, Alzheimer's Australia, https://fightdementia.org.au/national/campaigns/dementia-friendly-communities.

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[38] *Ministering to People With Dementia*, v, i. For more on the content of this resource, see slides from my presentation on 23 September 2015 to the clergy of the Catholic Diocese of Sale: "Dementia: A Challenge to the Church," Caroline Chisholm Centre for Health Ethics, http://chisholmhealthethics.org.au/system/files/2015_09_23_dementia.pdf. I speak to church groups to support the vision of creating dementia-friendly churches.

[39] *National Framework*, 10–12.   [40] Ibid., 16–17.

[41] See Australian Institute of Health and Welfare (AIHW), *Dementia care in hospitals: costs and strategies* (Canberra: AIHW, 2013).

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[48] See, for example, Nuffield Council on Bioethics, 128–142; and Alzheimer's Disease International, 77–78. [49] Dementia Collaborative Research Centres, http://www.dementiaresearch.org.au/images/dcrc/pdf/DCRCbrochure_2013.pdf. [50] National Health and Medical Research Council (NHMRC), "Specific elements of the Boosting Dementia Research Initiative," NHMRC, https://www.nhmrc.gov.au/research/boosting-dementia-research-initiative/specific-elements-boosting-dementia-research-initiati; Alzheimer's Australia (AA), "Research," AA, https://fightdementia.org.au/national/research-and-publications/research.

[51] NHMRC, "Boosting Dementia Research Initiative," NHMRC, https://www.nhmrc.gov.au/research/boosting-dementia-research-initiative; AA, "76 of Australia's best new research fellows receive funding to fight dementia," AA, https://fightdementia.org.au/about-us/news-and-media/media-releases/76-of-australia%E2%80%99s-best-new-research-fellows-receive-funding-to-fight-dementia.

All online material accessed 31 December 2015.

Kevin McGovern ✠

Being Mortal: End-of-life Care and End-of-life Discussions

Atul Gawande's book Being Mortal: Illness, Medicine, and What Matters in the End, *draws upon both anecdotal stories and literary sources to highlight the importance of honest discussions as the end of life approaches. These discussions are particularly significant for older persons and terminally ill patients. Gawande believes that these discussions could be*

facilitated by more in-depth and focussed communication between the healthcare professional and the patient. Respecting the patient's values and priorities, and promoting a sense of wellbeing and dignity are critical for quality care.

Atul Gawande is a Professor of Medicine at Harvard University, a surgeon, public health researcher and author. Encouraged by positive responses to his previous essays in The New Yorker,[1] he wrote *Being Mortal: Illness, Medicine, and What Matters in the End*.[2] The book explores the ageing process, the care of older persons in their frailty, the possible priorities of people as their independence declines, and the importance of having end-of-life discussions when death is inevitable.

Being Mortal has 282 pages—an Introduction, 8 chapters, and an Epilogue. The first chapter describes how the emerging concept of independence arose out of markedly improved social and economic circumstances, and how this has led to changes in family dynamics. This has resulted in a way of life which favours liberty and autonomy, thus shifting societal values away from family dependence to self-dependence. The second chapter provides a review of the trajectories of health, the process of ageing and decline, and some theories as to why we age. He highlights that both society and medicine have been slow to meet the challenges associated with an ageing population. The subsequent chapters describe how functional decline leads to dependency in older age, and how historical changes in the structure of medical care has led to the rise of nursing homes. Chapters 6 and 7 highlight the importance of having effective end-of-life discussions with older persons and terminally ill patients, and critique how medicine has failed to care for those who are most vulnerable. The final chapter of the book discusses the issues that arise as death approaches, based on the author's personal experience of his father's terminal illness and subsequent death.

Life, health and the process of ageing

The trajectory of life towards the process of dying has changed in recent times. Where once the trajectory of health towards death was abrupt, advances in medicine have significantly reduced the likelihood of premature and unexpected death—more people are living longer. Improved sanitation and other public health measures have also extended this longevity, slowing down the process of declining health as we age.[3] However, the inevitable process of ageing means that we will experience gradual, natural wear and tear and the eventual shut down of our bodies.[4] This gradual wear and tear over time increases our dependency on others.

Caring for the older person

In Western society, caring for the older person was traditionally a multigenerational responsibility, with the older person being cared for by the family at home.[5] A rising notion of independence fuelled by economic globalisation has led to more resources and opportunities being available to the younger generation, inclining them to leave the family home and "follow their own path."[6] Economic prosperity alongside healthier and longer lives has also enabled the older generation to live autonomously and with less infirmity for a longer period of time. These changes have resulted in different expectations for the family to care for the older person. However, society has failed to acknowledge the

reality of declining independence towards dependence as we age. This lack of acknowledgement impacts upon our ability to provide appropriate quality care for the dependent person.[7]

Gawande argues that historically, the rise of nursing homes to accommodate the growing number of older dependent persons in need of care occurred with the underlying notion that these vulnerable persons could be "nursed" back to health. Nursing homes, however, "were never created to help people facing dependency in old age."[8] He believes that the contemporary care of older persons is based on a medical and institutional model, and that this inevitably compromises the quality of care.

Whilst aged care facilities do provide some form of care for older persons, Gawande argues that these facilities may place undue emphasis on institutional goals and institutional routines. They may also have excessive concerns about the safety of residents.[9] Gawande maintains that all this is because they were established under a medical paradigm. Such facilities de-humanise the experience of dependent living, as they fail to acknowledge a person's sense of self and autonomy.[10] As a response to de-humanising experiences in nursing homes, the author notes that more people are choosing alternative forms of care such as hospice and palliative care.[11] In all this, Gawande identifies a concerning tendency in residential aged care. Good residential aged care facilities must be extremely vigilant to counter this potential problem in their model of care.

Hospice and palliative care

Palliative care focuses on wellbeing, pain management, and psychosocial and spiritual support for the patient who has a serious, life-threatening or terminal illness.[12] Hospice care, a subset of palliative care, is end-of-life care predominately for those in the final phase of a terminal illness. The author notes that hospice care is significantly beneficial for those who are terminally ill and nearing death.[13] Introducing palliative care soon after a diagnosis of a serious, life-threatening or terminal illness such as cancer, is associated with improvements in quality of life and extends patient survival.[14] This holistic practice of care would also be relevant for older persons in their end-of-life phase or as they move towards death. It is important to understand patients' perspectives, desires and goals, in order to provide quality end-of-life care. Receiving adequate symptom management, achieving a sense of control, and strengthening relationships with loved ones are important aspects of care for patients at this time.[15]

Importance of communication

Palliative care takes into account the views of the person in care.[16] Gawande mentions that the traditional paternalistic style of the doctor-patient relationship has impacted upon our ability to effectively communicate and offer genuine choices in treatment and care. He proposes that a more interpretative style—involving guidance from the doctor and emphasising shared decision making with the patient—is more appropriate for end-of-life care.[17] This type of relationship involves examining the underlying values of the patient and determining priorities which are important to them.[18] This approach in communication is beneficial as it informs the patient of realistic goals and expectations of treatment.

It is imperative that clear communication exists as over-estimation of treatment effectiveness and reluctance to disclose prognosis impair the doctor-patient relationship. Doctors are often reluctant to disclose an unfavourable prognosis[19] and overestimate survival rates of terminally ill patients.[20] This lack of honest communication inclines patients receiving treatment to have unrealistic expectations,[21] hoping for a cure where there really is none. Certain ethical issues may arise from this lack of effective communication at the end of life. These include the lack of truly informed consent whereby the patient is not aware of the futility of their treatment, and thereby makes uninformed choices which result in the prolongation of their own suffering and/or the suffering of their loved ones. This is of particular concern for patients with a poor prognosis and nearing death.

End-of-life discussions: Asking the right questions

Talking about death and dying can be a difficult task. End-of-life discussions and providing quality end-of-life care involve asking the right questions which go beyond discussing medical facts and treatment options. Gawande suggests that this involves simply asking about and understanding the priorities of the person at this time of their life, which is paramount to providing the best care for them. When time is limited, people have other goals and priorities besides just living longer.[22] The benefits of having these discussions include taking into consideration treatment preferences and preparing the person for the inevitable. This not only benefits the patient's wellbeing, but also helps caregivers cope with bereavement.[23]

Part of the task of asking the right questions involves helping people deal with both the internal anxieties associated with the process of dying, and the external anxieties such as concerns about loved ones.[24] The author notes that asking specific questions helps gather information about patients' values and priorities to facilitate this conversation. It would include asking the person what they understand about their prognosis. Other questions Gawande suggests include: "What are their concerns about what lies ahead?" "What kinds of trade-offs are they willing to make?" "How do they want to spend their time if their health worsens?" and asking who they want to make decisions for them if they are unable to do so.[25]

Further to asking about these priorities, determining the patient's values and worldview is important. These include having an understanding of any religious and/or spiritual affiliations the person may have. Awareness of cultural differences is also important as different cultures have different interpretations and understandings of illness and mortality.[26]

All of these values bring about a fundamental understanding of what is truly important to the person at this stage of life when time is limited. It promotes an inherent sense of dignity at this time of vulnerability. Dignity is the crux of Catholic Social Teaching which recognises that a human being deserves dignity at all stages of life, regardless of age or disability.[27]

Importance of dying

The author notes that Western society has lost touch with the benefits that the dying role gives to people who are at the end of life.[28] This loss may have resulted from Western culture's approach to death which tries to deny its natural process, and instead "battles" to avoid it at all cost. By contrast, taking on the dying role enables a person along with their loved ones to achieve important priorities such as passing on wisdom, leaving behind a legacy, and/or resolving unfinished business with loved ones.[29]

Although there has been a better understanding of the biological process of ageing, there is still generally a lack of understanding of the metaphysical, social and psycho-spiritual aspects of mortality—what it means to die—and what it means to live a good life. Additionally, society's reluctance to examine the experiences of the ageing process and of dying has increased the subsequent harm and suffering of patients, by imposing aggressive unwarranted medical treatments to the most vulnerable members of our society.[30]

Whilst the author accepts that for certain patients, suffering which is unavoidable and unbearable might be alleviated by physician-assisted suicide, he recognises that physician-assisted suicide would be detrimental to persons at the end of life.[31] He believes that legalising physician-assisted suicide may encourage the wider society to be dependent on this, and divert focus from improving quality end-of-life care. Recourse to assisted suicide, he notes, "is not a measure of success. It is a measure of failure." Gawande continues, "Our ultimate goal, after all, is not a good death but a good life to the very end."[32]

Strengths and limitations of the book

The book offers an engaging discourse in issues surrounding mortality and end-of-life care. By incorporating personal stories of older persons, those who are terminally ill and his own insight as a surgeon and public health researcher, Gawande brings a sense of authenticity and poignancy to the book. This authenticity is further highlighted by his use of literature to support his claims of the benefits of providing quality end-of-life care to patients and their families. While his inclusion of literature was relevant for Western culture, there was a lack of literature focusing on other cultural views of death, dying and end-of-life discussions.

Whilst the author anecdotally recounts his Indian grandfather's experience of decline into old age and compares it to Western viewpoint, it is from this Western perspective that his assertions regarding end of life are based. It is important to understand the diversity of cultural views as they create the context by which a person experiences life. These experiences are shaped by cultural understandings and expectations, and influence subsequent behaviours. In turn, these experiences may impact upon persons' preferences and priorities at the end of their lives.[33]

Throughout the book, the author rightly reiterates the need for better education surrounding the concept of mortality in the wider society so as to normalise what is an inevitable outcome of our existence as human beings.

Conclusion

Being Mortal provides an informative read for those who are interested in end-of-life discussions, including healthcare professionals, patients and/or families. Mixing personal stories and providing relevant literature to emphasise his assertions, the author details the importance of having end-of-life discussions, of normalising the process of dying in

society, and of recognising the limitations of aggressive medical treatment when death is imminent. Hospice and palliative care have enabled persons to maintain their autonomy and wellbeing at the end of their life cycle. This is due to the significant benefits of care that takes into account the person's values and priorities, which are often not restricted to just living longer.

Gawande argues that most aged care facilities do not sufficiently take into account their residents' priorities.[34] Aged care facilities have the potential to make an important contribution to end-of-life care by providing holistic care that does consider residents' priorities. It is imperative to appreciate a person's priorities at the end of life as it respects their inherent dignity as human beings, and assists them in living a good life right to the very end.

ENDNOTES

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[22] *Being Mortal*, 155.

[23] Ibid., 177–178. See also Alexi Wright et al., "Associations Between End-of-Life Discussions, Patient Mental Health, Medical Care Near Death and Caregiver Bereavement Adjustment," *The Journal of the American Medical Association* 300, no. 14 (2008): 1665–1673 at 1671, http://dx.doi.org/10.1001/jama.300.14.1665.

[24] *Being Mortal*, 182.

[25] Ibid., 182–183.

[26] Robert Blank, "End-of-Life Decision Making across Cultures," *The Journal of Law, Medicine & Ethics* 39, no. 2 (2011): 201–214 at 204, http://dx.doi.org/10.1111/j.1748-720X.2011.00589.x.

[27] Centacare Brisbane, *Ten Principles of Catholic Social Teaching*, 2015, http://centacarebrisbane.net.au/about/our-faith/.

[28] *Being Mortal*, 249.

[29] Linda Emanuel and Karen Glasser Scandrett, "Decisions at the end of life: have we come of age?," *BMC Medicine* 8, no. 1 (2010): 57, http://dx.doi.org/10.1186/1741-7015-8-57.

[30] *Being Mortal*, 9.   [31] Ibid., 245.   [32] Ibid.

[33] Blank, 204.   [34] *Being Mortal*, 76.

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Moral Distress

As health systems become more complex, moral distress is increasingly being recognised as a significant phenomenon amongst health professionals. It can be described as the state of being distressed when one is unable to act according to what one believes to be morally right. It may compromise patient care, the health professional involved and the organisation. Cumulative experiences of incompletely resolved moral distress—a phenomenon which is called moral residue—may leave us susceptible to more frequent and more severe moral distress. Clear open communication, respect, inclusivity, openness to differences, compassion, support, education and the capacity to grow in self-awareness are key aspects in minimising moral distress. Early recognition of its symptoms and addressing both personal and external constraints of actions can also minimise moral residue and build resilience to further distress.

Moral distress can be described as the feeling or state of being in distress when one is unable to act according to what one believes to be morally right. This 'morally right' conclusion is often framed by one's worldview, which incorporates values, experiences, knowledge and understanding, and one's meaning and purpose in life. For example, the inability to inform a 12-year-old patient that she is dying because her parents forbid it, may cause moral distress in the medical team who believe the patient—even when young—has the right to know. Another example of what might cause moral distress is when a member of an executive team is compelled to abide by the decision of the whole team, even though the member believes that decision to be morally wrong or (at least) less morally right.

Unless addressed, the accumulation of such unresolved distress may lead to burnout, loss of self-confidence and self-esteem, chronic fatigue, social withdrawal and isolation, loss of purpose, physical illness, even leaving the workforce. Using the medical approach to illness—understanding the illness, primary prevention, recognition of symptoms and signs, investigation, management and secondary prevention (of further illness)—this article offers a framework for minimising moral distress and its adverse consequences. Whilst it is written in the context of healthcare, the approach could also be relevant in other fields.

Understanding Moral Distress

Distress is one of the many emotions that may arise in the context of moral dilemmas or conflicts. Moral distress was first described in the 1980s in the setting of the nursing profession.[1] Over the years, this phenomenon is being

recognised in other areas such as business, finance and politics, and at all levels, from governance to grass-roots.[2] Two related issues are at play: the moral dilemma or conflict, and the constraints both personal and external "that prevent one from taking actions that one perceives to be morally right."[3]

Moral dilemmas often arise when there is a conflict between two morally obligated right actions such that each can be done but not both together.[4] In the first example above, the medical team has an obligation to care for the child which involves truth-telling and transparency. This means informing her that she is dying, especially if she asks them directly, perhaps enabling her to live her dying days well and prepare for death. However, they also have an obligation to honour the wishes of the parents who are legally responsible for the child and who seek to act in what they consider to be her best interest.[5] These parents may believe strongly that informing their child of her prognosis would cause her to become deeply depressed. The dilemma of what to do may lead to moral distress for the medical team, especially if they believe that the obligation to tell the truth overrides any risk of depression that *may* ensue for the child.

Moral distress may be complicated further by personal constraints such as a lack of self-confidence and questioning one's own ability to discern.[6] External constraints such as hospital policies and procedures, a refusal by management to listen, and a legal team enforcing parents' rights (possibly for fear of a lawsuit), can also aggravate moral distress. Conflicting cultural and religious beliefs, communication breakdown, resource allocation,[7] institutional constraints, lack of receptivity to queries, and varying philosophical and moral orientations amongst health professionals[8] are highlighted in the literature as additional factors contributing to moral distress.

Primary Prevention

If conflicting moral obligations is the source of moral distress, it follows that resolution of that conflict would minimise, if not alleviate, this distress. Of paramount importance is clear communication with all involved regarding the facts of the illness and the treatment options.[9] This also involves each party sharing with all concerned, the many reasons, both medical and moral, for choosing a particular action.[10] Understanding the varying perspectives—especially that of the patient—alongside an attitude of openness to change, may result in a consensus.

Another consideration is the culture of the healthcare organisation. A culture which considers each employee only as a mechanical piece within a machine, to be discarded when non-functional or dissenting, would contribute to moral distress. On the other hand, a culture that considers each employee as part of and belonging to an evolving organization would contribute considerably to the *prevention* of moral distress. Employees who feel constrained from exercising their moral judgements for fear of repercussions would be encouraged instead to contribute to the moral integrity of the organisation through their questioning. The provision of support systems such as employee assistance programmes (EAP), ethics committees, critical stress debriefing, grief counselling,[11] approachable managers and mentors, and human resources personnel sensitive to the concept of moral distress, are most important.

In summary, then, the prevention of moral distress can be aided by: good communication amongst all concerned parties; attitudes of respect, inclusivity, openness and compassion, desiring only the good of the patient (and community); self-awareness, understanding one's own values and agendas, re-formulating them if appropriate, and not imposing them inappropriately on others; organizational flexibility and support; and genuine moral deliberation.[12]

Symptoms and signs

Recognition of the emotions, particularly of distress, related to moral dissonance is the first step in the healing process. Psychological distress symptoms such as anger, anxiety, frustration, over-thinking, fear, guilt, withdrawal, fatigue, sleeplessness and physical ailments[13] may be attributable to other causes such as relationship difficulties, sudden death or being sued. However, these symptoms are a manifestation of moral distress when they are "the result of a perceived violation of one's core values and duties, concurrent with a feeling of being constrained from taking ethically appropriate action."[14] Hanna proposes further that the harm is "tied to the intrinsic purpose of a person"—what one's purpose in life is—described by Aristotle as innately towards the good.[15] It is important to distinguish the causes of distress as it helps determine the course of action.

Cumulative experiences of incompletely resolved moral distress—defined in the literature as moral residue[16]—may lead to the progression of emotional distress from loss of self-confidence, to loss of integrity[17] and identity, burnout, disenfranchisement, and significant ill-health.[18] Another outcome of the crescendo effect of unresolved moral distress and cumulative moral residue is the re-setting of one's threshold for moral distress to a lower level. This is described as the worsening of an individual's moral resilience which, in turn, can result in an increase in the number and severity of episodes of moral distress.[19]

The best path is to recognise its early signs. Moral discomfort for instance may include feelings of disquiet or uneasiness when considering the context or situation in which these feelings arise.

Investigation

Having recognised these emotions, it would be important to note the facts of the situation and name the issues and values that appear to be contravened. Is this truly a moral issue or is it something else like, perhaps, a reaction to suffering? Is there a communication issue? Are the patient and family aware of all the facts: treatment options, prognosis, and illness progression or outcome? Is the discomfort or distress arising from conflicting subjective moral values—of self, other health professionals, patient, patient's family or organisation—or from ethical requirements related to the role such as patient advocacy?[20] If it is the former, do we need to re-assess our own moral values and perhaps our worldview? If the latter, do we need to understand the reasoning behind the ethical requirement of the role in order to allay the discomfort or distress? Are the constraints for moral action internal or external to the individual? What are the opinions or teachings of experts such as ethicists, professional organisations, and other specialists? Do other colleagues feel the same, giving further credence to the moral conflict? Is any further information needed? Is there an underlying power-dynamic at play

between the health professionals, patient, family members, and/or the organisation?[21] Does this situation highlight unresolved experiences of past moral distress?

The management of moral distress

Having both determined that moral distress is present and identified the issues contributing to it, the next step lies in discerning how to manage it at the personal, group (those involved in this particular situation) and organisational level. Communication of the facts of the illness, treatment options and prognosis, including different underlying values and beliefs, spirituality, past experiences and worldviews, may be a first step. It calls for an openness of mind and heart to this shared wisdom by those listening. A nonjudgmental and safe environment allows for venting of emotions and expression of fears and vulnerability, which, in turn, are compassionately held by others. Once people feel heard and respected, conversations can begin, enabling each one to see different points of view and possibly shift their stance, leading to a consensus for the way forward.[22] Guidance from professionals such as ethicists is also encouraged.[23] The way forward may include reaching a compromise: owning what is one's personal morality without enforcing it on the patient; and/or coming to a place of not necessarily agreeing fully with everyone but being able to 'live with' the decision; being able to find meaning and purpose in the final outcome, making the decision acceptable. Understanding the context of and principles of decision-making in a particular incident may aid in transforming dissonance to harmony, and even, to acceptability, hence alleviating or resolving the moral distress.

At the personal level, the psychosocial aspects of moral distress need to be addressed. Seeking social supports from colleagues, trusted friends and mentors may aid in this. Assistance from professional organisations (e.g. medical or nursing) may be beneficial. The courage needed to take action begins with a commitment to address the moral distress in order to preserve one's "integrity and authenticity."[24] Caring for the self is encouraged as a high priority. This includes addressing tiredness, vulnerability, feelings of isolation that may ensue. Utilising organisational resources such as counselling via EAP, clinical ethics services, ethics committee members, line managers or department heads, could be other avenues of support. Lützén and Kvist also propose an attitude of recognising moral distress as a "positive catalyst in exercising moral agency."[25]

On rare occasions where no ethical resolution is foreseeable, the individual needs to discern whether they need to maintain their integrity and follow their informed conscience,[26] or to accept that the outcome is outside their control and that they have done everything possible to alert others to the moral wrong in play. The former may mean suffering some alienation and/or seeking employment elsewhere; the latter may result in compromising and letting go of responsibility, and in this way coming to some measure of peace within.

At the organisational level, recognition of the significance of moral distress amongst staff is a moral imperative. In this regard, worthwhile strategies include making resources available to those in distress: EAP; easy access to the clinical ethics service and/or ethics committee; clinical supervision whether internal or external to the organisation; and the education of both staff and human resources personnel on

moral distress. All these steps not only indicate a valuing of all staff but also help build a robust moral community.[27] The organisation could undergo regular reviews of policies and procedures according to outcomes of ethical dilemmas and investigations of staff moral distress.

Secondary Prevention

As we recognise and grow in awareness of moral distress, secondary prevention involves ensuring that the issues which may lead to moral distress are addressed early. Enabling open communication at all times, exploration in an attitude of openness and respect of the values and beliefs of others that seem contradictory to one's own, and naming fears, are examples of what can be done as secondary prevention. The experience of moral distress often heightens the sensitivity to moral conflicts that may lead to another episode of distress. This sensitivity can alert one to address these issues and hopefully to resolve the conflict or dilemma before it escalates.

Building moral resilience is another aspect of secondary prevention. Monteverde suggests that moral resilience can be built with adequate moral knowledge, skills training such as communication and ethical decision-making, and promotion of attitudes such as "truthfulness, confidentiality, self-reflexivity, responsible scholarship."[28] These aspects of moral resilience building can be exercised with each experience of resolving moral distress, and as Monteverde suggests, with healthcare ethics education. He warns however that moral resilience without outcomes of moral action or deepening of moral understanding can lead to moral apathy, burnout, even fanaticism.[29] Lützén and Kvist add another perspective of moral resilience in exploring Viktor Frankl's experience, defining moral resilience as "a concept that can be defined as a distinctive sense that life is meaningful under every condition."[30]

Making resources available for staff, as mentioned above, is another measure of secondary prevention. Included in these resources could be clinical ethics services, ethics committees with a consultative subcommittee, or, as suggested by Epstein and Delgado, moral distress consult services.[31]

Conclusion

Moral distress is our Whole-Person way of recognizing that something is not right in the way we relate, or in our relationships within the environment in which we have our being. How we relate is based on our perspective and our expectations of ourselves and others. This in turn finds its roots in our values, belief systems, experiences, intuition, reasoning and knowledge. It is an evolving stance even as our interactions and relationships evolve, and therefore cannot happen in isolation. The proposal to exercise our moral agency through the perspective of the whole as well as the individual is an invitation to recognise that each has a share of the wisdom regarding the right moral act.

In the case of moral conflict and the distress that can arise from it, the opportunity for growth and true discernment lies particularly in our openness to listen to the Spirit through others. Ensuring open communication, adequate and appropriate resource allocation, staff support, ethics education, respect for each person involved—including cultural, religious, philosophical and moral differences—is a step towards minimising moral distress. Experts such as ethicists and clinical ethics services skilled in mediation may

assist in reaching consensus as to the way forward, or assist the individual in resolving their conflict. In some cases, allowing time and space for those involved to come to terms with what has happened may be all that is needed to comprehend fully the situation at hand and move forward.

Being conscious of the existence of moral distress, recognising the early signs, managing and resolving it, learning from the experience and putting into place strategies to minimise it in the future, at the individual, communal and organisational level, are necessary ways of diffusing this potential time bomb. It is yet another aspect of healing and whole-making to which we have committed ourselves as health professionals, and as human beings.

ENDNOTES

[1] Andrew Jameton, *Nursing practice: The ethical issues.* London: Prentice-Hall, 1984. For a description of the evolution of the understanding and concept of moral distress since Jameton, see Kim Lützén and Beatrice Ewalds Kvist, "Moral Distress: A Comparative Analysis of Theoretical Understandings and Inter-Related Concepts," *HEC forum* 24, no. 1 (2012): 13–25 at 16–17. For a discussion of the definition of moral distress and a critique of the usefulness of Jameton's definition, see Debra R. Hanna, "Moral Distress: The State of the Science," *Research and Theory for Nursing Practice* 18, no. 1 (2004): 73–93.

[2] Joshua E. Perry, "Managing Moral Distress: A Strategy for Resolving Ethical Dilemmas," *Business Horizons* 54, no. 5 (2011): 393–397. See also Markus Christen et al., "Measuring the Moral Impact of Operating 'Drones' in Pilots in Combat, Disaster Management and Surveillance," *Proceedings of the European Conference on Information Systems (ECIS) 2014, Tel Aviv, Israel, June 9-11, 2014, http://aisel.aisnet.org/cgi/ viewcontent.cgi?article=1160&context=ecis2014.* Though focussed on the moral distress of drone pilots, this study can be extended to higher levels of political decision-making in political moral dilemmas.

[3] Elizabeth G. Epstein and Ann B. Hamric, "Moral Distress, Moral Residue, and the Crescendo Effect," *The Journal of Clinical Ethics* 20, no. 4 (2009): 330–342 at 331.

[4] Terrance McConnell, "Moral Dilemmas," *The Stanford Encyclopedia of Philosophy* (Fall 2014 Edition), ed. Edward N. Zalta, http://plato.stanford .edu/archives/fall2014/entries/moral-dilemmas/. In #2, McConnell writes, "The crucial features of a moral dilemma are these: the agent is required to do each of two (or more) actions; the agent can do each of the actions; but the agent cannot do both (or all) of the actions. The agent thus seems condemned to moral failure; no matter what she does, she will do something wrong (or fail to do something that she ought to do)."

[5] Hugo Gold, Georgina Hall, and Lynn Gillam, "Role and Function of a Paediatric Clinical Ethics Service: Experiences at the Royal Children's Hospital, Melbourne," *Journal of Paediatrics and Child Health* 47, no. 9 (2011): 632–636 at 634.

[6] See also Elizabeth G. Epstein and Sarah Delgado, "Understanding and Addressing Moral Distress," *Online Journal of Issues in Nursing* 15, no. 3 (2010), endnote #3, http://gm6.nursingworld.org/MainMenuCategories /ANAMarketplace/ANAPeriodicals/OJIN/TableofContents/Vol152010/No 3-Sept-2010/Understanding-Moral-Distress.aspx.

[7] Gold, Hall, and Gillam, 634. Although the article highlights common features of case consultations at the Royal Children's Hospital, it is likely that these cases resulted in sufficient moral distress in staff for them to seek the assistance of the clinical ethics service.

[8] Barbara K. Redman and Sara T. Fry, "Nurses' Ethical Conflicts: What Is Really Known About Them?," *Nursing Ethics* 7, no. 4 (2000): 360–366 at 365.

[9] This would include the healthcare team, the patients and their extended family members and loved ones.

[10] Two sessions are envisaged here: the first within the healthcare team, including each member of the team with differing views; and the second within the context of the situation, that is between the healthcare team, the patient or surrogate, the family and perhaps the ethics committee members.

[11] American Association of Critical Care Nurses (AACCN), "Position Statement on Moral Distress," (Aliso Viejo, CA: AACCN, 2008): 1–3 at 2, http://www.aacn.org/WD/Practice/Docs/Moral_Distress.pdf.

[12] See Ibid., endnote #10. The concept of *moral deliberation* is an example of this process. It is described by Molewijk et al. as "a pragmatic-hermeneutical and dialogical" approach to ethics. It is a dialectical approach whereby the 'truth' is arrived at through reasoned dialogue. In this, the final conclusion may not be in keeping with the original opinions. Albert C. Molewijk et al., "Teaching Ethics in the Clinic: The Theory and Practice of Moral Case Deliberation," *Journal of Medical Ethics* 34, no. 2 (2008): 120–124.

[13] American Association of Critical Nurses (AACCN), "The 4 A's to Rise Above Moral Distress," (Aliso Viejo, CA, AACCN, 2004): 1–11 at 3, http://www.aacn.org/wd/practice/docs/4as_to_rise_above_moral_distr ess.pdf. Other physical, emotional, behavioural and spiritual signs of suffering are well-described and listed in this resource.

[14] Epstein and Hamric, 331.

[15] Hanna, 77.

[16] Epstein and Hamric, 333.

[17] For a further discussion on moral integrity and its complexities, see Lorraine B. Hardingham, "Integrity and Moral Residue: Nurses as Participants in a Moral Community," *Nursing Philosophy* 5, no. 2 (2004): 127–134.

[18] Mary C. Corley, "Nurse Moral Distress: A Proposed Theory and Research Agenda," *Nursing ethics* 9, no. 6 (2002): 636–650 at 637. See also Hardingham, endnote #17.

[19] Epstein and Hamric. See also Hanna.

[20] Hanna.

[21] Edison Luiz Devos Barlem and Flávia Regina Souza Ramos, "Constructing a Theoretical Model of Moral Distress," *Nursing Ethics* (2014): 1–8.

[22] Molewijk et al.

[23] Some organisations have a clinical ethics service whose function is "the provision of advice and support on ethical issues arising from clinical practice and patient care within a health care organisation." For more on this, see Anne Slowther et al., *A practical guide for clinical ethics support* (Oxford: The Ethox Centre, 2004), 6, UKCEN Clinical Ethics Network, http://www.ukcen.net/uploads/docs/education_resources/ prac_guide.pdf; National Health and Medical Research Council (NHMRC), *Clinical Ethics Capacity Building Resource Manual*, NHMRC, http://www. nhmrc.gov.au/guidelines-publications/e114?utm_medium=email&utm_ campaign=Release+of+the+Clinical+Ethics+Capacity+Building+Resource+ Manual&utm_content=Release+of+the+Clinical+Ethics+Capacity+Buildin g+Resource+Manual+CID_bd722f50dd92e39f20d2921eed113150&utm_ source=Mailbuild&utm_term=Clinical%20Ethics%20Capacity%20Building %20Resource%20Manual; and Catholic Health Association of the United States of America (CHAUSA), *Striving for Excellence in Ethics: A Resource for the Catholic Health Ministry* (Washington, DC: CHAUSA, 2009), 28–30.

[24] AACCN, "The 4 A's," 2. This resource for critical care nurses may also be useful for those seeking to address moral distress. The approach of the 4A's is a cyclical one which involves Asking so that one is aware of the presence of moral distress; Affirming the distress and making a commitment to address it; Assessing the distress determining the source, severity and readiness to act; and finally taking Action and maintaining the desired change.

[25] Lützén and Kvist, endnote #1. Lützén and Kvist further describe moral agency as "a multifaceted phenomenon beyond a single theoretical approach but can be regarded as consisting of moral knowledge, moral judgment and moral motivation, in which moral distress also plays a role." For this, see Lützén and Kvist, 22.

[26] For a detailed understanding of what informed conscience entails, see Kevin D. O'Rourke and Philip J. Boyle, *Medical Ethics: Sources of Catholic Teachings*, 4th ed. (Washington DC: Georgetown University Press, 2011), 24–32.

[27] Hardingham.

[28] Settimio Monteverde, "Caring for Tomorrow's Workforce: Moral Resilience and Healthcare Ethics Education," *Nursing ethics* (2014): 1–13 at 4.

[29] Ibid., 10.

[30] Lützén and Kvist, 320.

[31] Epstein and Delgado, 8.

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