



SPEAKING OF SUFFERING

Towards a conversation
about death and dying

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Executive summary

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Australians are understandably reluctant to contemplate death, but there is a need for a public conversation about issues relating to sickness, death, and dying.

Based on a survey of the academic literature on dying and end-of-life care, this paper identifies some of the key issues that need to be discussed as part of that conversation.

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Speaking of suffering

INTRODUCTION

Like many people in developed countries, Australians seem reluctant to contemplate illness, aging, and dying. To the extent that there is anything like a public conversation about what used to be called our mortality, it is marked by fears of suffering and the loss of dignity and autonomy as the result of a chronic or end-of-life illness. For perfectly understandable reasons, these anxieties shape our attitudes to getting older, the possibility of contracting serious illnesses, and the inevitability of death.

A public conversation about sickness, death, and dying and the part they play in what it means to be human could be beneficial at many levels, not least for the consideration of questions such as euthanasia and assisted dying, which increasingly dominate the discussion in this space. The starting point is to address these primary concerns. It is vital that any public conversation involves an accurate understanding of the responses and attitudes of people with a serious illness or at the end of life, and what exacerbates or relieves suffering in these situations. An examination of the growing research into the experiences and concerns of those who are sick and dying reveals a number of important insights into these questions.

This paper draws on a survey of some of the academic literature on the perspectives of people confronted by death, dying, suffering, and illness. It highlights several essential themes that regularly appear in the studies about prevailing attitudes, responses, difficulties, and avenues for care that people experience while sick at the end of their lives. A particular point of interest for the paper are the symptoms, circumstances, and attitudes that prompt people to find their suffering unbearable and their lives no longer worth living.

The survey found that there is also significant psychological, social, and existential suffering experienced by people at the end of life. These other kinds of suffering have an array of causes. They stem from the painful symptoms of the illness, a person's response to the facts of their illness and approaching death, and the conditions and quality of their care and surroundings. These symptoms and sources of physical, psychological, and existential suffering prompted people with end-of-life illnesses to report that their suffering was unbearable. As a result, for these people, life was no longer considered to be worth living. Suffering was, thus, found to affect the whole person, including their sense of dignity, their sense of self, and their sense of meaning in life. The survey also identified potential avenues for reassurance and holistic treatment for the sick, suffering, and dying. These avenues, provided through palliative care, assist people in alleviating physical pain, maintaining their dignity, and finding meaning and hope.

This paper is intended as a contribution to an informed public conversation about the perspectives of those who are sick, suffering, and dying and what has been found to improve their situation. In addition to a survey of some of the academic literature into the experiences and care of those with end-of-life illnesses, it also draws on anecdotal findings from researchers and people working in palliative care about the attitudes and responses of people with end-of-life illnesses. The purpose of the paper is not to provide an assessment of how many people suffer or how likely anyone is to suffer at the end of life, but to identify how people are suffering and what might aid in relieving that suffering. The paper summarises the findings of some of the research in this area and offers some concluding suggestions about how this evidence might be used to inform a public conversation about sickness, aging, and the end of life. The hope is that a public conversation informed by an accurate understanding of the common responses to sickness and dying will heighten awareness of the concerns that are the most significant for people at the end of life, as well as the avenues of information about treatment which can aid and reassure those who are sick, suffering, and dying.

THE SYMPTOMS OF SUFFERING IN PEOPLE AT THE END OF LIFE

Researchers into the suffering experienced by some people at the end of their lives have described this suffering as an “all-encompassing” experience [1]. Suffering was also found to be a very individual and subjective experience that is unique to that particular person [1-3]. The vast majority of the research surveyed agreed that suffering at the end of life goes beyond the direct experience of physical pain, as intense as that may be, and affects the whole person [4-6].

Physical suffering

The focus of public discussion about end-of-life experience, not least in the context of the debate over euthanasia or assisted dying, often centres on the physical pain experienced by some people who are dying. Some people experience pain, loss of bodily function, fatigue, or cognitive impairments [7-9]. Physical suffering also includes other symptoms of pain and discomfort such as nausea, vomiting, shortness of breath, nightmares, and delirium [10-12]. One study reported that physical suffering was cited as the “biggest fear” for people in critical conditions, who envisioned future pain that would be unbearable and “worse than death” [5, 13, 14]. In another study, one patient described his experience with the symptoms of his illness by saying, “pain affects everything” and it “takes that life out of you” [5]. Others noted that, although they would like to live, they felt that they could not live this way, and under these conditions, any longer [5, 15].

Psychosocial and existential symptoms

In addition to the physical symptoms caused by an end-of-life illness, several psychosocial symptoms were also experienced. The literature concluded that psychosocial suffering occurs co-morbidly with physical illness, and the presence of one has been found to inflame the distress experienced by the other [1, 5]. Together, the physical and psychosocial suffering takes a toll on a person's sense of self, their perception of their dignity, and their sense of meaning in life [4, 5, 16].

Psychosocial distress was often manifested in symptoms of anxiety, fear, anger, grief, depression, uncertainty, and a desire for hastened death [1, 8, 12]. Especially evident in those people who were recorded as having expressed a desire for a hastened death were symptoms of depression and anxiety disorders [14, 17, 18]. As a result, the common symptoms of depression, which include loss of interest or pleasure in usual activities, loss of energy, fearfulness, and recurrent thoughts of death, were observed in those who suffered at the end of life [5, 19, 20]. In addition to symptoms of psychological and emotional distress, those suffering from end-of-life illnesses were recorded as experiencing symptoms of existential and spiritual suffering such as feelings of helplessness, hopelessness, meaninglessness, and loneliness [12, 21, 22]. Several studies concluded that these psychological, social, existential, and spiritual sources of suffering experienced in end-of-life illnesses were more prominent and caused more significant distress than the symptoms of physical pain [4, 14, 15].

The desire for a hastened death

Most studies of end-of-life suffering reported numerous causes which sometimes led to the desire for a hastened death [7, 12, 23]. The desire for a hastened death in patients is itself a symptom of the multi-faceted distress evident in end-of-life illnesses. Several studies show that the physical symptoms of pain only have a limited impact on the desire for a hastened death [4, 12]. Those who had expressed a wish to die had higher levels of depression, hopelessness, and dismissive attachment (attachment to others characterized by independence and self-reliance), and lower levels of spirituality [9]. Although many factors have been identified as contributing to a person expressing a wish to die, it has also been shown to be a fluctuating and unstable feeling in people towards the end of life [5, 16]. Importantly, the research found that the request to hasten death may also constitute a request for help and a desire to communicate about living with the physical, psychosocial, and existential suffering that they feel, when this suffering overwhelms them and has become unbearable [2, 12, 15].

PSYCHOSOCIAL INFLUENCES ON END-OF-LIFE SUFFERING AND PSYCHOSOCIAL CARE

As a result of the prominence of psychosocial symptoms of suffering in those at the end of life, there is substantial exploration in the literature of the multiple causes of psychological, psychiatric, and social distress. These sources of suffering include psychological disorders, the phenomenon of death anxiety, the fear of being a burden, and the distress caused by inadequate social support and isolation.

Psychological disorders

Even outside of psychologically diagnosed conditions, anxiety about the approach of death and potential suffering can manifest itself in worries and stresses about medical complications and the uncertainty of prognosis, and as anxiety prompted by social and financial concerns [19, 24, 26]. Even though some of these symptoms are part of normal emotional responses to sickness and suffering at the end of life, they are also reflective of the higher likelihood of diagnosable psychological disorders such as depression and anxiety [24-26].

Researchers found a particular connection between people suffering from depression and the desire for a hastened death [14, 16, 19]. One study reported that patients who had expressed a desire for a hastened death were up to four times more likely to suffer from depression than patients who did not express this desire [16]. Another reported that rates of depression had the most significant correlation with the desire for death [10]. In addition, it was noted by researchers that there was a correlation between an end-of-life illness and the intense suffering of anxiety, fear, and worry [10, 24]. People suffering at the end of life were also found to be at a higher risk of reactivating the symptoms of a pre-existing mental illness [6]. However, one study noted that the majority of those who requested a hastened death did not have a history of psychiatric illness, indicating that their psychosocial condition was prompted by their recent experience of illness at the end of life [11]. The conclusion from the research was that psychological illness and psychiatric disorders were found to exacerbate the physical symptoms of a patient's illness and contribute significantly to their suffering at the end of life [9, 25, 26].

Death anxiety, death awareness and death acceptance

Beyond the evidence for the experience of psychological distress in those suffering from end-of-life illnesses, one of the main findings of this research has been evidence of death anxiety [25, 27, 28]. A certain level of stress about death occurs in people of all ages and regardless of their circumstances or experiences of suffering [28]. However, death anxiety is a term used in the academic literature to describe the unhealthy attitudes and responses of fear, anxiety, and

uncertainty that stem from a person's recognition of the prospect of their death [6, 26]. For those who experienced death anxiety, distress was observed to increase with a deterioration in the patient's physical health, and the exacerbation of mental health disorders and preventable health behaviours [25, 28]. Another researcher concluded that dispelling the fear of death was vital for discovering peace at the end of life [17]. Interestingly, the highest levels of death anxiety were recorded in the middle-aged, rather than in the elderly [25, 29, 30].

As a result of the anxiety that surrounds the prospect and reality of death, researchers found that there is a tendency in people to avoid the fear and anxiety that results from thoughts of death by avoiding the topic of death or illness altogether [27, 28]. Researchers have also noted the adverse effects of avoiding awareness of the prospect of death. In one study, researchers concluded that concerted efforts to avoid thoughts of death might increase fear and psychological distress during an end of life illness [27]. Another study recorded that avoidance and denial of death prompt psychiatric morbidity, physical discomfort, and functional impairment in palliative care patients [26, 27]. Death avoidance, thus, has implications for a person's preparedness for end-of-life illnesses and suffering. One study found that those who did not acknowledge their prognosis were nearly three times more likely to be clinically depressed than those who demonstrated partial or complete acknowledgment [17]. In addition, death avoidance is, in the long term, impossible as the circumstances of life make the reality of mortality unavoidable.

Given that avoiding awareness of death is impossible, there comes a point at which people need to accept the inevitability of their mortality. Death acceptance thus describes a set of attitudes and psychological adjustments in which a person no longer avoids the prospect of their death but instead accepts its inevitability and relative immediacy [13, 27, 30]. Researchers have identified different kinds of death acceptance, including what they describe as "negative death acceptance". A negative approach to accepting the inevitability of death refers to people who are convinced that the negative aspects of living while dying and suffering are worse than death itself [13, 31]. These people, thus, accept the reality of their death as an escape from pain, loneliness, or reduced quality of life [27, 31]. Those with acceptance problems were more likely to display symptoms of anxiety and depression, hopelessness, and moderate to severe suffering [5, 26, 27]. One study found that anxiety adjustment disorders are often prompted by the uncertainties, fears, and lack of acceptance that accompany a prognosis [6, 10, 26]. Another study found that roughly half of those who suffered from acceptance problems at the end of life showed symptoms of anxiety and depression, hopelessness, and moderate to severe suffering [26].

Social Issues

Another essential theme of the research literature is the influence of social factors on the sick and dying. Significant symptoms of social distress, like lower family cohesion, lower

social support, and a higher perception of being a burden were found to increase suffering in people with end-of-life illnesses [12, 14, 17].

One of the most significant sources of social distress for those suffering at the end of life was their reported loss of cohesive community and social connection [1, 5, 14]. One study found that depression in people with end-of-life illnesses was negatively correlated with perceived social support [9]. Several studies reported the necessity for those suffering from illness at the end of their lives to feel supported and cared for by their family members [6, 10, 21, 23, 32]. This need for social support also extended to medical professionals. One study claimed that patient suffering and loss of dignity and self-esteem could be exacerbated by medical professionals failing to respond to a patient's needs or failing to communicate adequately [32, 33]. Another study found that limited training in psychological care and counselling in medical professionals was associated with a higher likelihood of the patient wishing to hasten their death [14]. In addition, the research documented that the suffering person, whether because of inability or lack of desire, often reported difficulty communicating to those around them about the suffering that they were experiencing [1, 13].

Suffering at the end of life was described in the research as being an alienating experience, and critically ill patients were reported as being vulnerable to loneliness [18]. Loneliness, alongside social isolation and lack of a supportive network, was also given as a reason why some who were seriously sick at the end of life expressed a wish to hasten death [12, 32, 34]. One researcher noted that a poor environment and institutionalisation were correlated with barriers to adequate social support [11]. Another study claimed that those who were institutionalised were more likely to have depression and high levels of death anxiety [25]. One researcher summarised the situation by reporting that "Patients at [the end of life] require constant care, support, and the feeling of love and connection to others" [26].

Fear of being a burden

One of the most prominent responses in those who are sick and dying is that they feel that they have become a burden to their families. Prompted by losses of functionality and independence caused by their illness, the feeling of being a burden is a significant source of distress for those who are suffering and dying [4, 16, 17]. The need to depend on others was often found to prompt feelings of shame, blame, frustration, and low self-esteem [4, 23]. The research reported a correlation between the feeling of being a burden and depression, hopelessness, and feeling a loss of dignity [4, 17, 20]. The fear of being a burden predominantly affected people's perception of their social support after witnessing and feeling responsible for the impact of their illness and suffering on their families and caregivers [16, 23]. People who reported that they felt like a burden to others also assumed that their family members or caregivers likewise viewed them as a burden [4, 10]. One researcher said that this feeling remained in some even though they knew that they were

accepted and willingly cared for by their caregivers [12]. As one patient was reported to say, “No matter how much they love you, you are always a burden. You automatically become a burden to everyone” [5].

For these reasons, the feeling of being a burden was experienced as continual suffering. One study reported the distress of one patient who said, “I would like to go. You see, I want to let people off the hook. I don’t, I don’t like it that they always have to . . . they all have a life too” [12]. The possibility of hastening death was, therefore, seen by some as the only way for them to cease being a burden [4, 5, 15]. Another study claimed that the fear of being a burden represented the highest independent association with the wish to hasten death [14]. The feeling of being a burden ultimately impacts a person’s self-perception and prompts them to feel that they have lost independence, competence, and dignity [5, 7, 12].

Carers’ influence and fatigue

Following the research on the importance of social support for people during the end of life, there has also been significant research into the fatigue that family members and carers experience in caring for those with end-of-life illnesses. The literature reveals the high social, economic, and psychological cost of end-of-life caregiving exacerbated by the extent of the patient’s suffering, inadequate resources, and unrealistic expectations of themselves as caregivers [6, 21, 33]. The research concludes that caregiving could be burdensome, especially when it involves restricted activity, uncertainty, loneliness, and lack of support [8, 21]. Caregivers with low levels of support and high levels of fatigue were also recorded as experiencing depression and high levels of hopelessness, sometimes to an extent beyond that of the patients themselves [26, 33]. This indicates that families and caregivers also need significant emotional and practical support in caring for their loved ones who are suffering and dying.

LOSS OF AUTONOMY AND DIGNITY

Another regularly stated concern and cause of suffering in those who are sick and dying is the perception by the suffering person that they have lost their dignity and autonomy.

These people describe how the experience of physical deterioration, loss of physical function, and cognitive impairment affects their sense of self and their quality of life [1, 6, 32].

This, when coupled with the increased dependency caused by their illness and the loss of autonomy over their lives, led many at the end of life to report feeling that they had lost their dignity [4, 17, 23]. One study claimed that the loss of dignity was a more consistent predictor of suffering at the end of life than physical symptoms [26].

Dignity

The literature reveals two commonly held understandings of the concept of dignity. First is the understanding of a ‘basic’ or ‘intrinsic’ dignity, which indicates an “unconditional quality of human worth” [6, 32]. However, more common in discussions of end-of-life suffering is ‘personal dignity’, which is related to a sense of identity that a person holds that can be influenced by physical, psychological, spiritual, and social factors [5, 6, 32]. This sense of personal dignity and identity can be severely diminished in those who are sick and dying.

Those who reported no longer having a sense of their dignity attributed this loss to a range of causes. First, physical symptoms such as pain, fatigue, physical weakness, incontinence, and the loss of bodily function were all recorded as diminishing a person’s sense of their dignity [6, 16, 32]. These physical experiences were also found to be related to social and existential factors that impacted perception of dignity [6, 26, 32]. These factors included the perceptions of being disempowered and embarrassed by the symptoms of their illness, feeling devalued or useless to those around them, and feeling forced into a demeaning situation that eliminated what made life enjoyable and worthwhile [1, 11, 16]. Other social influences on how the sick and dying perceived their dignity included cases where people felt that they were not adequately heard, informed, or respected as decision-makers, either by their caregivers or by healthcare professionals [5, 23, 32]. Researchers also identified a correlation between the perceived loss of dignity with depression, hopelessness, and the feeling of being a burden [4, 5, 15]. No longer being able to live as they once did, or to do the things that they found meaningful, people who suffered at the end of their lives reported feeling stripped of their independence and sense of self [6, 12, 32].

Autonomy

The feeling of lost dignity was closely tied to losses in basic functionality, quality, and enjoyment of life as well as to the value that a person placed on their autonomy and independence [7, 16, 32]. The researchers reported that those who felt that they had lost their autonomy expressed feelings of fear, helplessness, and the loss of self-esteem in connection with their loss of functionality and quality of life [5, 15]. No longer having control over bodily function, their immediate environment, their social role, or their day-to-day activity was the cause of significant distress and suffering [6, 30, 33]. One study recorded a person saying that, “I lost my dignity, lying in bed in diapers, I am no longer the independent person I used to be” [5]. Dignity is, thus, understood by many to consist of having the ability to perform essential functions independently and enjoy a certain quality of living [11].

As a result, autonomy, independence, and control were prominent concerns of those who were sick and dying. Sufferers reported that significant distress was caused by the fact that their physical condition had made them utterly dependent on others [9]. Transitioning from a state of self-sufficiency and independence, which they felt was critical to their sense of self, to a state

of total dependency caused people to feel helpless and even self-loathing [4, 5, 17]. The research revealed that those who tended to pursue assisted dying were more likely to be described by their physicians as “independent”, and as expressing a “desire to control the dying process” [9, 12, 26]. One researcher noted that “the anticipated dependency of terminal illness possibly may have been more unbearable than the physical symptoms themselves” [9]. The loss of control over their lives and the inability to escape from or have power over their present circumstances was the cause of significant distress in the sick and dying [23, 32, 33].

The research stated that people who had reported feeling that they had lost their dignity and autonomy expressed a desire to regain control over their lives [6, 32, 33]. This desire, according to the research, appears to be a response to feelings of helplessness and hopelessness in the face of their illness [1, 5, 15]. The wish to hasten death was expressed with the hope of regaining control over their physical symptoms and regaining a sense of their identity [9, 12, 19].

Effect of the loss of dignity and autonomy on the whole person

The experience of the loss of dignity, thus, affects the whole person and diminishes a person’s sense of self-worth and identity, and causes intense personal suffering to those who are dying [6, 20, 32]. As a prominent palliative care researcher, Harvey Chochinov, noted, “If dignity can be understood as deserving honour, respect, or esteem . . . [these findings] suggest a self-perception wherein patients no longer consider themselves worthy of these attributes” [6]. This is especially the case when suffering and dying people, as well their caregivers and medical professionals, understand dignity to be reflective of a person’s ability to possess the kind of quality of life that they choose.

The importance of a person’s perception of their dignity is identified in the research as being closely connected with a person’s spirituality, sense of meaning, and how they cope with the existential challenges of life-threatening disease.

HOPELESSNESS, MEANING AND SPIRITUALITY

In addition to the suffering prompted by perceptions of lost dignity and autonomy, the research uncovered that people who were seriously sick, suffering, and dying displayed symptoms of existential distress. The research frequently referred to existential—or spiritual—suffering as distress that was caused by the loss of meaning, purpose, and hope and was found by researchers to be significantly related to a person suffering harm to their sense of spiritual well-being, identity, and personhood [17, 22, 23]. Existential suffering for those at the end of life was most commonly experienced as feelings of hopelessness and the loss of meaning from life.

Hopelessness

Many of those suffering from end-of-life illnesses reported feeling hopelessness and helplessness at the end of their lives [6, 8, 9]. Researchers found that hopelessness and despair are experienced by those at the end of life who come to believe that change in their illness, environment, or circumstances is impossible [1, 19, 22]. Hopelessness was prompted by awareness of the terminal nature of an end-of-life illness, the inevitability of death, and the experience of losing what was valuable in life [5, 8, 12]. The loss of hope for any improvement in life's circumstances—not just for recovery from illness—was strongly correlated with the fear of future suffering and negative future expectations [1, 15, 20].

Hopelessness was also prompted by the loss of control that the ill, suffering, and dying experienced at the end of life and was related to their inability to change or escape their present circumstances [9, 12]. One study recorded the experiences of patients, one of whom reported: “You lie in bed and none of the normal functions come back. They will never come back and it will only get worse” [5]. Another in the same study reflected on “the end of many dreams for plans . . . the end of it all. There's no future really” [5].

Hopelessness and despair were found by researchers to be significant predictors of the desire for a hastened death and the willingness to consider assisted suicide [5, 20].

Hopelessness was also strongly correlated to the presence of depression [1, 10, 22]. One study claimed that it was hopelessness, not the actual state of physical dependency, that was most strongly correlated to the feeling of being a burden [1, 6].

Loss of meaning

The extent to which a sick, suffering, and dying person finds meaning in their day-to-day life was found by researchers to significantly impact the suffering of a person at the end of life, particularly existential suffering. One researcher found that the extent to which cancer patients attributed meaning to their situation was the single best predictor of their levels of anxiety and self-esteem [5, 17, 26]. Many seriously ill or dying people expressed their feeling that their condition had caused their life to lose meaning [1, 12, 16]. For these people, their suffering and their illness had stripped their lives of the quality and value that it once had [5, 9, 33]. The loss of meaning was a common finding in people who also claimed to have lost their sense of self-identity and purpose for continuing living [4, 6, 32].

Many patients described examples of the quality that their life once held, and expressed the view that because they could no longer perform these activities that they once found meaningful, their life had become meaningless [5, 15, 29]. For those who highly valued autonomy and independence, the suffering of sickness and dying meant that they were no longer able to live the life that they found meaningful [9, 23]. The research revealed that those who were not able to find meaning in the process of dying saw assisted dying as the only way

to avoid meaningless suffering [5, 29, 35]. One researcher claimed that “rather than being an attribute of suffering, loss of meaning is suffering” [1].

Spirituality and spiritual wellbeing

According to the research, spirituality could be identified irrespective of religion. The literature described spirituality as reflecting a person’s source of meaning, purpose, and hope [1, 17, 20]. Beyond hope in an afterlife, spiritual wellbeing was found to connect to what a person identified as most valuable and essential in everyday living [17, 27]. One researcher defined spirituality as “the way in which people understand their lives in view of their ultimate meaning and value” [22]. It was, thus, important for people to discover a personal and interior motive that made life worthwhile, despite the pain and suffering that they were experiencing [1, 20].

Researchers noted numerous examples of people at the end of life exhibiting spiritual and existential distress that manifested itself in symptoms of fear and anxiety [17, 32]. One researcher found that poor spiritual wellbeing was strongly correlated with hopelessness and the desire for a hastened death [6]. Other researchers noted that poor spiritual wellbeing was related to expressions of hopelessness, helplessness, depression, and despair [9, 22, 26]. One researcher claimed that “spiritual well-being was a strong correlate of end-of-life despair, providing a unique contribution to the prediction of hopelessness, desire for hastened death, and suicidal ideation even after controlling for the effect of depressive symptoms and other relevant variables” [22].

Another study found that low spirituality and loss of meaning emerged as the strongest predictor of seeking aid in dying [9]. The research also claimed that spiritual beliefs and practices are often identified as necessary to an individual’s overall quality of life, as these enabled people who were sick and dying to cope with their suffering [9, 27]. There is also a clear connection in the research between spiritual wellbeing and the presence of hope, with researchers finding a correlation between hopelessness and poor spiritual wellbeing [6, 17].

AVENUES FOR TREATMENT AND SUPPORT

One of the key takeaways from the research is the conviction among researchers and palliative care professionals that the most prominent symptoms of physical, spiritual, and existential pain could be treated through palliative care [3, 11, 20]. Good palliative care was found to preserve and restore the perception of dignity and hope in those who were sick and dying [10, 14, 26]. As one researcher observed, what was most important was that “Patients wanted to belong, be loved, valued, affirmed and nurtured as human beings, and to be respected with dignity” [33]. Contributions to this kind of care can be made by all sorts

of people. In particular, the research established the overwhelming importance of medical professionals to the holistic care of the sick, suffering, and dying as they are uniquely placed to offer support to people in their time of distress [5, 14, 17]. In addition, there is a significant role for family members and other caregivers to supply support [4, 13, 17].

As a result of these findings, and given that people who suffer at the end of life have a wide variety of needs that correspond to all of the aspects of their personhood, the research confirmed that a holistic approach to end-of-life care that treated physical, psychosocial, and existential suffering together was crucial [1, 26, 32]. This holistic approach, and the avenues for treatment and support that it prompts, was found by the research to have a significant dissipating effect on the fears, hopelessness, and suffering of people who were sick and dying [1, 6, 32].

Results of physical care

It is important to begin any discussion of potential avenues for treatment and support of the sick and dying by stating that adequate treatment for the physical pain and suffering ought not to be understated just because of the prominence of psychosocial or existential concerns [11, 12]. One research article claimed that where there is adequate treatment for physical pain, in conjunction with the treatment of psychological disorders, the wish to hasten death decreases [12]. The treatment of physical symptoms and the maintenance of a comfortable environment were also found to help address some of the psychological symptoms that were being experienced, such as anxiety [7, 11, 35].

Results of psychosocial care

Also vital in the care of people at the end of life is providing adequate treatment for psychological and psychiatric conditions. One study reported that suicidal ideation receded upon the treatment of pain and depression [15]. Psychological support, counselling, and therapy were also found to be necessary in addressing the feelings of loneliness and isolation experienced at the end of life, as well as functioning as an outlet for fears and anxieties [3, 11, 32].

In addition, the research found that it was important for people at the end of life to have good social supports and maintain good relationships [7, 9, 19]. This highlights the importance of vulnerable and suffering people feeling that their concerns are being heard and that they are respected and cared for by those around them [16, 33]. These social connections were found to help reduce the influence of loneliness and fear of being a burden in people in palliative care [6, 8, 16]. People at the end of life were found to need companionship and some ability to contribute and care for others while in a state of heavy dependency [4, 33]. Medical professionals were also found to play a crucial role in informing and supporting the families and caregivers of the sick and dying [13, 30]. One study found that adequate communication

from health professionals early in the illness, especially in the case of terminal illnesses, significantly reduced anxiety and psychological distress in the patient [13]. This kind of communication was vital in helping those who were sick and dying feel listened to and respected [32, 33, 35]. Adequate communication also helped people suffering from severe illnesses maintain a level of agency in their care [4, 5, 15]. One study recorded a case in which genuine social contact and moral reassurance from health professionals were essential in helping a patient feel that they deserved the care that they were receiving [12].

Existential and spiritual care

Another important source of care for people with end-of-life illnesses targeted their spiritual wellbeing [6, 20, 22]. Those who were motivated by a personal life meaning were found to be able to deal with suffering and uncertainty at the end of life [27, 36]. The research found that religious and spiritual people were less likely to report death anxiety, hopelessness, and perceptions of meaninglessness [6, 9, 19]. The research also found that those with higher levels of spirituality and religiosity were more likely to find meaning in life and report higher levels of hopefulness [23, 32, 33]. In addition, researchers found that those individuals who were generally satisfied with life were better able to accept the prospect of their deaths and to find meaning in their remaining days [9, 27, 30]. As a result, even amid their suffering, they were able to avoid the fear and anxiety commonly experienced by severely sick and dying people [19, 22]. Instead, they were reported to have continued motivation to live through whatever suffering they were experiencing in the present [12, 21, 33]. One researcher reflected on the thought that “the sting of death is swallowed up by our engagement in a meaningful life” [27]. As a result, there is a high priority in palliative care on spiritual and existential treatment that can help people overcome their fear, find hope and meaning in their day-to-day life, and restore a person’s perception of their dignity [6, 20, 32]. The research found that people who received good spiritual and existential care were more likely to report a sense of empowerment, confidence, self-esteem, and will to live [1, 17, 19].

Examples of positive death acceptance included people who were convinced that what they found meaningful in life was not diminished by the prospect of their death [13, 27, 33]. Whether this acceptance was based on their hope in their spirituality and the afterlife, or the pursuit of meaning in the present life, such people were found to have stronger self-esteem and better “existential well-being” [13, 27, 36]. Thus, these people approached the end of their lives as another avenue for the meaning already entrenched in their lives. This finding is consistent with the results of other studies which stated that death anxiety decreases in those who can overcome despair and come to accept their situation [6, 19, 27]. Another study found that death awareness led to a more substantial commitment in some to pursuing and strengthening their close relationships [29].

The literature uncovered multiple avenues for restoring the senses of dignity, meaning, and spiritual well-being for patients who were suffering and dying. These avenues of treatment,

such as cognitive therapies and dignity-conserving care, attempt to identify and conserve what was most fundamental to a person's identity, sense of meaning, and purpose [19, 20, 32]. Because every person's approach to their dignity and purpose is different, this means uncovering those indignities that have been experienced by a person suffering at the end of life, as well as recognising them as a person [6, 20, 33]. In addition, allowing space for the discussion and resolution of spiritual matters, with health professionals, family members, and other specialists, helped patients resolve matters of spiritual and existential distress [10, 26, 33].

One example of helping to restore a sense of dignity that was advocated by the research, known as dignity therapy, allowed people at the end of life to recount their achievements and what they found to be meaningful and important in their lives [6, 15, 32]. One researcher reported that, following his efforts to recognise a patient's accomplishments during their life, "He was no longer simply an elderly male with an oral malignancy and secondary complications, admitted for palliative care, but someone deserved of honour, respect, and esteem—words corresponding to the definition of dignity itself" [20]. The experience of being listened to, respected, and validated had a significant impact on the way that people viewed themselves and their dignity [10, 32, 33]. The care that prioritised the alleviation of a person's indignities, hopelessness, meaninglessness, and weak spiritual wellbeing, was thus found by the research to be vital to the care of people suffering from illness at the end of life.

CONCLUSIONS FOR A PUBLIC CONVERSATION

What is evident from this survey of the literature is that there is a range of circumstances under which people can suffer when they are sick and dying. However, it is important to note that consistent quantitative data is difficult to obtain. This paper has largely avoided referring to it because of the existing limitations of surveying people who are suffering at the end of life. Nevertheless, there are still some important takeaways from the qualitative research that would be important to emphasise in a public conversation about death and dying.

Making it known that effective avenues of treatment exist is a key starting point for a public conversation on end-of-life suffering and sickness. This is especially important given that palliative care remains underfunded and unavailable to many people [2]. The average person, informed by the popular conception that suffering is unbearable and untreatable at the end of life, still seems to be unaware that pain and suffering can be managed and alleviated to a significant extent. Given that the research noted the impact that witnessing a painful or horrible death can have, it is important to highlight examples of good natural deaths.

It is crucial to note that intervening care does not necessarily make physical care symptoms disappear. Instead, good palliative care and social support from loved ones and caregivers makes it possible to provide physical, psychosocial, and spiritual comfort that can manage the symptoms of suffering. There is, perhaps, even less awareness of how palliative care offers various forms of care to address psychosocial, existential, and spiritual suffering, and how it

can help to alleviate the fear of dying, the fear of being a burden, and the loss of dignity and autonomy. A public conversation should try to increase significantly broader understanding of the difference that holistic approaches to palliative care can make at the end of life and in life-limiting illnesses.

Given what the literature highlights about death anxiety and the adverse effects of avoiding awareness of the prospect of death on patients, a public conversation in any form must not avoid the fact that dying can be very difficult for some. This means that it is essential to be clear about what can and cannot be achieved through end-of-life care. This is especially the case if the goals are to foster greater openness about discussing the end of life and dying, and to offer some reassurance that people do not need to die alone and in pain, without dignity or hope. The success of a public conversation focused on openness and reassurance depends precisely on dealing with the reality of death in an honest and sensitive manner.

In light of observations in the research about how crucial medical professionals are to good end-of-life care, it is important to moderate expectations about medical professionals and what they can do, while also supporting efforts to strengthen good communication between them and patients and their families. As stated earlier, although palliative care and modern medicine can achieve so much in the alleviation of suffering at the end of life, it is not a magical cure-all. At the same time, good communication from medical professionals makes it easier to accept the limitations of treatment and the prospect of dying. Communication which emphasises listening to patients, taking their wishes seriously, responding to their concerns sensitively, and not losing sight of the suffering person looking to them for information and care, is critical to the contribution medical professionals can make to preserving a patient's sense of being valued and worthy of the care they are receiving.

One of the most interesting takeaways from the research is the importance of social support and good communication for the alleviation of suffering and the maintenance of a person's sense of personhood and dignity. This still leaves significant scope for examining what causes distress in the social environments of those at the end of life. Although the literature documents the negative social effects that medical professionals can have on patients through poor communication and undignified treatment, there is little data about how negative family dynamics can affect a person's psychosocial and spiritual wellbeing. Awareness of elder abuse is gaining prominence following the Royal Commission into Aged Care Quality and Safety and the recognition of the extent to which institutionalisation can negatively affect people at the end of life. What some of the literature highlights about the significance for people at end of life feeling that they can still help to care for those close to them and strengthen their most important relationships suggests that a public conversation should turn attention to how people can contribute very meaningfully to those around them, even when dependent or terminally ill. This is important in helping to shift public perceptions of the end of life and dying away from strong associations with uselessness, humiliation, and being nothing more than a burden on others.

One of the key conclusions from the survey of the literature is that there is substantial research into the phenomena of death anxiety, and the awareness, avoidance, and acceptance of death. These subjects connect to the prominence of fear in attitudes and responses to sickness, suffering, and death, especially before people are themselves sick or dying. There is a significant opportunity to address this by prompting awareness of death and illness long before people find themselves unprepared and anxious in the face of the end of their life. This is also connected with how people recognise meaning and dignity in their lives, before they are in an end-of-life situation. What we might conclude here is that there is a need to explore the possibilities for engaging people about the prospect of their deaths before the point when they find themselves with an end-of-life illness. A public conversation might open up the difference between positive and negative ways of accepting the inevitability of death, and the different effects they can have on people when they find themselves at the end of life. It could also encourage reflection upon what is important to us, and how this can help or hinder a sense that what is meaningful in our lives, and makes us who we are, is not taken away by sickness and dying.

This leads to discussing the importance of dignity and autonomy for people's attitudes towards end-of-life illnesses and end-of-life care. Everything in the research this paper surveyed points to the value that people place on autonomy. There is a sense in the literature that people understand maintaining their sense of their dignity, autonomy, and quality of life to be the most fundamental components of a life worth living.

The emphasis in Australian society on the loss of dignity and autonomy seems to be based in life-long values and interpersonal qualities. These themes lie at the heart of concerns about end-of-life suffering. The full significance of dignity and autonomy for many people in Australian culture is beyond the scope of this paper. Nevertheless, it should form part of a public conversation, focused particularly on what we understand by dignity and autonomy, and whether there are better, more life-enhancing understandings of them that give us more to rely on and more to sustain us when we confront our own deaths.

From this survey of the research, it seems that the highly personal sense of autonomy and dignity that many Australians have is profoundly undermined by the experience of disempowerment and dependency which is part of the end of life. Exploring the idea that autonomy and dignity are better grounded in mutual dependence rather than self-reliance is perhaps another contribution that a public conversation could make to our society's understanding of the end of life and the meaning of death. The literature shows how agency and self-esteem can be preserved and even restored at end of life by communication, connection, being able to care for others, and a sense that what is most important to a person is not diminished by death. It would be a benefit to all of us, not just in thinking about our own mortality but in reflecting on what it means to be human, for this evidence to be better known and more widely discussed.

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The survey of the research on which this paper is based was not intended to meet the criteria for an academic literature review. Instead, the aim was to cover a selection of articles for an informal survey of the literature. This survey covered forty-five articles with only those with information used in this final summary listed below. The survey only covered pieces written since 1995 to cover the period since the brief legalisation of euthanasia in the Northern Territory in 1995.

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Speaking of Suffering: Towards a conversation about death and dying

This paper provides a survey of qualitative research on contemporary attitudes to suffering at the end of life.

It explains that the research identifies three forms of suffering at the end of a person's life: physical suffering, psychosocial suffering, and existential suffering, which are interrelated.

The paper considers the sources of psychosocial suffering in particular, how this gives rise to a feeling of loss of dignity and agency, and how this in turn can result in existential suffering caused by feelings of hopelessness and loss of meaning.

Some conclusions of the research about the importance of palliative care are also sketched out, as well as findings about the way in which adequate spiritual care can address psychosocial suffering, which in turn helps a person manage physical suffering.

The paper is intended to contribute to establishing the basis for a more informed discussion about public policy relating to death, dying, and end-of-life care in Australia.

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Cover image

Robert Moore, *Late evening* 2016 Australia (detail).

Oil and enamel on board.

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