

“I wouldn’t want to become a nuisance under any circumstances”—a qualitative study of the reasons some healthy older individuals support medical practices that hasten death

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Abstract

Aim To explore the reasons some healthy older New Zealanders support medical practices that hasten death.

Methods Recruitment was from the Voluntary Euthanasia Society of New Zealand (VESNZ), an organisation that supports legal medical assistance in dying. All participants were members of VESNZ. 106 individuals returned signed consent forms. All interviews took place in the participant’s home. After 11 interviews, saturation of information was reached and interviewing was stopped.

Results An important finding of this study indicates that healthy, older individuals who support medical practices that hasten death have serious concerns about their (perceived) future incapacities and dependency on others, as well as their fears around becoming a burden. The study also found that fear of future pain was not a dominant reason to support medical assistance to die.

Conclusion Our study provides confirmation that the fear of being a burden on others is not only felt by those facing their imminent mortality, but also by older individuals who are currently healthy and living independently in the community. We also conclude that for some older people their prior experiences with health care and dying may be a strong factor in influencing and supporting medical practices that hasten death at the end of life. We believe it is crucial to understand the reasons why people support medical practices that hasten death well in advance of such practices ever becoming legally available.

Support for medical assistance in hastening death appears to be growing both around the world and in New Zealand. This is evidenced by the fact that in the past decade a number of countries and states have legislated for euthanasia and/or physician-assisted suicide to be made available to patients in carefully qualified situations (the Netherlands, Belgium, and Luxembourg)¹.

Presently, the states of Oregon, Washington and Montana in the USA allow for physician-assisted suicide. Laws in Switzerland accommodate assisted suicide that does not necessarily involve assistance by a physician.

Over the past 2 decades a number of studies have examined the attitudes of terminally ill patients²⁻⁵ and physicians⁶⁻⁸ towards medical practices that hasten death (euthanasia and physician-assisted suicide). For instance, Wilson et al⁹ found that psychological

aspects may be as important as physical symptoms for cancer patients who would actually make a request for their death to be hastened by a physician.

Johansen and colleagues¹⁰ also investigated attitudes towards physician-assisted dying with cancer patients who had a life expectancy of less than 9 months. They found that whilst some patients held positive attitudes towards euthanasia and physician-assisted suicide, the wish to die was ambivalent and fluctuating: a mental 'solution' for the future. Further studies have explored physicians' experiences of end of life decision-making¹¹⁻¹⁵.

Furthermore in New Zealand, two surveys of the general population concluded that around 70% of New Zealanders support medical assistance in hastening death when someone is terminally ill and their suffering is intractable and unbearable.^{16,17} Some general practitioners in New Zealand consider it justifiable¹⁸ and some do intentionally end the life of a patient who is incurably ill.¹⁹ Despite this, practices that hasten a patient's dying are neither lawful²⁰ nor openly practised in New Zealand.

To date no study has explored the reasons healthy, older people might have for supporting medical practices that hasten death. Examining the reasons some individuals have for supporting these practices is important in understanding how individual circumstances may influence personal decisions concerning medical care and treatment at the end of life. For instance, in understanding the factors involved when requests are made to withdraw or withhold medical treatment, or in the preferences expressed in advance care directives.

Furthermore, exploring the preferences an individual has regarding end of life decision-making may help health practitioners develop more patient-centred care plans at the end of life.²¹

The present study set out to explore these reasons in the New Zealand context.

Methods

Study design and ethics—A qualitative approach was used to explore the reasons some older healthy individuals support medical practices that hasten death at the end of life.

University of Auckland Human Participants Ethics Committee approval was obtained for the study (UAHPEC Reference number 2010/055).

Sample selection—Recruitment was from the Voluntary Euthanasia Society of New Zealand (VESNZ), an organisation that supports legal medical assistance in dying. All participants were members of VESNZ; some participants were also members of EXIT International. VESNZ Head Office forwarded 330 letters (from the researchers) advertising the study to Auckland members of the society inviting them to participate in the study. 138 people contacted PJM via phone, email or letter enquiring about the study.

All individuals who self-identified as healthy and were 65 years or older were sent information packs: these contained a participant information sheet explaining the study and what it entailed, a consent form, and a self-addressed envelope. 106 individuals returned signed consent forms which were numbered as they were opened. Every tenth participant was chosen for interviewing, with the exception of one spouse who was also interviewed (convenience sampling). Participants were then phoned by KM to ask about a convenient time to meet.

All interviews took place in the participant's home. After 11 interviews, saturation of information was reached and interviewing was stopped.

All participants lived in their own homes (one woman lived with her daughter), and all identified as healthy. None of the respondents had long term disabilities and were in fact remarkably healthy, except for an 89 year old woman who had mobility issues related to age-onset illness. This was not long-term, although she did not expect it to improve.

Participant numbers 4 and 4a were husband and wife.

Table 1. Demographic details of participants.

ID	Age	Gender	Religious affiliation	Living situation
1	79	female	No religious affiliation	Lives alone
2	78	male	Atheist	Lives alone
3	80	female	Baptist	Lives alone
4	82	male	No religious affiliation	Lives with wife
4a	86	female	No religious affiliation	Lives with husband
5	80	male	No religious affiliation	Lives with wife
6	88	female	No religious affiliation	Lives alone
7	89	female	Quaker	Lives with daughter
8	81	male	Atheist	Lives alone
9	69	male	Agnostic Christian	Lives with wife
10	75	male	No religious affiliation	Lives with partner

Data collection—Semi-structured interviews were conducted based on open questions concerning past experiences with death and dying, planning for end of life, concerns or fears about dying, reasons for joining VESNZ and/or EXIT. Interviews were conducted by one of the authors (KM) in respondent’s homes, and took approximately 1 hour.

The phrase ‘medical practices that hasten dying’ referred to interventions by a doctor that either assisted a patient to die (as in giving the patient the means to end their own life at their explicit request—physician-assisted suicide), or directly ended a patient’s life (as in a lethal medication administered by a doctor at the explicit request of the patient—euthanasia).

Interviews were recorded and transcribed. Each respondent was sent two copies of their transcript and asked to read and delete or alter any information they believed was inaccurate or did not represent their views. Once the transcripts were forwarded to the researchers they were used for purposes of analysis.

Analytical strategy—Our aim was to derive themes and meaning from the interviews. To do this we employed the grounded theory approach whereby responses in each previous interview were incorporated into the interview structure for subsequent interviews²². Interviews were imported into QSR NVivo 8 and subjected to multiple close readings by KM in a general inductive approach to identify broad categories of subject beneath which were identified themes that were coded for further analysis²³. All three authors then separately read the interview sections and the final identification of themes and selection of representative quotations was by agreement.

Results

Participants’ demographics—All participants were aged 65 years or older at the time of interview. Compared to the over 65s in the 2006 New Zealand Census, our sample were more likely to be European (100% cf 80.56%) and to have no religious affiliation (73% including atheists cf 11.8%).

Participants’ responses—It became clear during the analysis that participants’ reasons for supporting medical practices that hasten death were deeply intertwined and not easily captured in separate categories.

This can be seen in the interview with the first participant. She began by reflecting on caring for her mother more than 50 years ago when she was in her mid-20s and appears to incorporate this memory into her fears of being a burden on her own children:

Although I didn't know it at the time she had cancer throughout her body [...]. I was the last one to get married so she lived with me. [...] It was a family responsibility

I just feel that I don't want to be a burden on my children. And when I get old I don't want them to have to look after me. Um, it's just too hard for them, I don't want to do that to them

While the genesis of this fear of being a burden may have been in her memories of caring for her mother, it appears to have been awakened by a recent experience of visiting a friend with Parkinson's disease, in a rest home (nursing home):

I have been to see them and those people; they are just waiting around to die. It's awful, it's just awful

Participants' reasons for supporting medical practices that hasten death at the end of life were clustered around four main categories: concern for self at the end of life, concern for others, prior observed experiences with health care, and suicide issues. The first three categories are the subject of this paper. Themes identified under these categories are reported in italics.

Concerns for self at the end of life—*The desire to remain independent* and active for as long as possible was raised by several participants in our study:

Yeah. It's got to be an independent life, I mean I really don't think I want to live in a wheelchair in an institution you know (8)

Oh God, I can't imagine not being independent (6)

A fear of pain and suffering at some future point in time was given as a reason for supporting assisted death, as was the need to maintain one's dignity at the end of life:

My fear is pain and not being able to you know, live an independent life ...I certainly don't want to be incontinent lying in a hospital bed with no hope of ever getting better. Even if the pain could be dulled, it'd still be (8)

That's the, that's the insidiousness of aging. I worked this out. I might have a small pain and I think oh, that's okay, I can live with it. And a week later it might be slightly worse and I think, oh, I can live with it. And a week later it will be slightly worse and then you go on and realise about a year later, you know, that life hasn't got much value because of the physical pain. And you just keep going on. Well I don't want to do that (1)

Autonomy was important to several participants who spoke strongly about their right to make their own decisions about what they wanted at the end of life, and less about the actual reality of what they could or could not accept:

I cannot understand as I said right to start off with, why other people think they have got the right to tell me that I can't die when I want to and I don't see why I have to be desperately ill and talk to lord knows how many doctors to convince these people because I might not be in a state where I could convince anybody. All I know is that I know myself... Being in that sort of position and everybody's thinking that they're doing – they know better than we do and '*you shouldn't think like that dear*', and all the rest of it. What the hell? I mean we've both gone 80, [...] we've got the right to clear off when we want to (4)

I want to be aware enough to say 'no'. And I'd like to be able to do something about it while I have sufficient power (1)

Being useful appeared to be a bridge between concern for self and concern for others and was mentioned by several participants as a reason to go on living:

Yes, I think it comes down to what I can contribute, how useful I am. And when I'm useless and have nothing to contribute and can't look after myself. I think that's when I would wish to do something about it (1)

One woman questioned whether she would be missed by her family if she suicided and then recalled how much her daily phone calls meant to her granddaughter and great granddaughter who lived overseas:

....my calls every day, I know she looks forward to them. I know she doesn't always speak [to me for long] but that's the only thing I might be, I feel, of some use. But then I'm not going to try to hang onto a life where there's nothing there. I mean that would be terrible (6)

Concerns for others—A negative alteration in mental and physical abilities and body image can lead to a negative concept of self.^{24,25} Arguably in age, this is occurring at a time when a positive self-concept particularly in relation to loved ones becomes increasingly relevant to quality of life.

For many participants, the desire to be remembered 'in a good way' by loved ones is important. It was clear that individuals wanted others to remember them as someone who was both physically and psychologically healthy, and not as one who was now a shadow of their former self:

And I feel that when I get to that stage, I won't be like I am now. I won't be as they know me now, I will be somebody else who they, well they're sort of stuck with really (1)

I wouldn't want my grandchildren or daughters to see me at a stage when I am not the person that they always remember me as (5)

A desire not to be a drain on health care resources and society was articulated by several participants:

And I rather annoy I suppose a lot of my contemporaries because I really feel that, the old people around are a drain on resources. Well we are, it's a fact (6)

Being a burden or nuisance on others was a concern for a number of participants. It is a concern found in other studies:²⁶⁻²⁸

Knowing that you are a nuisance to everybody and getting little sympathy from caregivers frequently, um, even from family. You know you are a nuisance, a drag on them. I wouldn't want to become a nuisance under any circumstances (3)

Well if I was so physically handicapped that I couldn't do anything myself, if I needed attention all the time I would hate that. And um, and also if my mind was so unclear that I was just a trial. [...] Yes. Oh yes, I would hate to be a trial to people (7)

Becoming dependent on others for personal care and hygiene appeared related to being a burden, and troubled some individuals:

....if you couldn't do your basic care, couldn't wash yourself or go to the loo (toilet) by yourself, I don't want to go on after that. Thank you. And I don't expect (husband) wants me to go on like that either, or my family (4a)

One man spoke of his horror at the thought of having to be toileted:

When I can't wipe my own bum I want to be gone (2)

Prior observed experiences with health care—A number of participants began their interview discussing the decline and (in some cases) death of a family member or

friend and how those experiences had influenced their views around the dying process.

The experience of seeing family members or friends in long term care also profoundly affected some participants. For some the experience happened several decades before.

One man said of his experience of visiting a long term care facility:

I've visited one of these old age peoples' places and oh what depressing places they are. I love organ music so I play the church organ. And I got dragged into going there one night and playing hymns for them and arrggh (expression of disgust). God, most of them had gone, you know (8)

The experience of witnessing the decline of friends and family involved issues around how pain and suffering was (mis)managed, the prolonged duration of an illness (such as Alzheimer's disease) and its effects on the family, having to do everything for another person, and concern about lack of dignity in dying. Some participants were adamant that as a result of their experiences, they did not want to move into long-term residential care.

Agich²⁹ notes that "in our culture it is less death than long-term care that strikes us as so repugnant". He argues that long term care has become associated with images of frailty and despair, loneliness and destitution. For some individuals in our study their prior experiences with long term care reinforced both their need to be self-reliant and independent for as long as possible, and their aversion to dependency and need.

My wife had an uncle who was just a couple of years older than her and he had a heart attack when he was about 40-something after we were married and he lost the power to move his arms and legs and would speak a little bit and effectively my wife looked after him for years and years and years and years.... and I used to go around there twice a week for half a day and do everything that he needed. And I just thought how horrible it would be in that state (5)

And my mother died at 90 and she had Alzheimer's [disease] for 20 years, and I'd go and see her every fortnight and my last remaining brother would do alternate weeks and we did that and it is very distressing to see that happen. And I'd hate to see me in similar circumstances (9)

I'm one of six brothers, four of whom have died. Three from cancer related illnesses and they died in their mid-50s, quite a short lifespan in my opinion and their passing, well their illness was quite devastating you know to witness what they had to go through and I thought well, if there was something I could have administered to stop their pain and suffering, I thought I would or I'd probably do it (9)

Discussion

Like many industrialised countries, New Zealand faces the challenge of an aging population. As expenditure in health care increases with age, understanding the issues and preferences that influence the health care decisions made by older individuals would seem to be an important aspect of providing good medical care. This is especially so when older individuals may be considering their choices and making decisions about the kind of medical treatment and care that is appropriate for them at the end of life.

Our participant group comprised individuals who are members of an organisation that supports legal medical practices that hasten dying at the end of life. We chose to focus on this group of individuals because they had made a conscious decision to become

members of VESNZ and therefore had (presumably) given some thought to why they supported medical assistance to hasten death.

An important finding of this study indicates that some healthy, older individuals who support medical practices that hasten death have serious concerns about their (perceived) future incapacities and dependency on others, as well as their fears around becoming a burden. We also found that fear of future pain was not a dominant reason to support medical assistance to die. These findings also suggest that for some older people, their prior experience with health care and dying may be a strong factor in supporting medical practices that hasten death at the end of life.

The fear of becoming a burden on others is well documented within the end of life literature³⁰⁻³³ although the majority of studies explore the concept of being a burden in persons with a terminal illness.^{26-28, 34,35} Our study adds to the current body of research that fear of being a burden on others is not only felt by those who are terminally ill and facing their imminent mortality, but also by older individuals who are currently healthy and living independently in the community.

It is important to note that as individuals move through various stages throughout their lives their views on, and support of, many things may change. The person who fears disability or increasing dependence on others may reason that a future that includes these would be unacceptable to them.

Our research shows that for some individuals, support for medical assistance to hasten death may be in response to concerns such as these.

There is evidence from the Netherlands, and Oregon and Washington States (USA) that many individuals whose requests for an assisted death are approved by doctors, are not actively assisted to die at the end of life, or do not choose to use the lethal medication they have been prescribed³⁶⁻³⁸. For instance, in Washington in 2010³⁷, 87 individuals were prescribed lethal medication under the Death with Dignity Act.

Of the 67 individuals who died (for whom an After Death report was received by the Washington State Department of Health), 15 did not use the lethal medication to end their lives. While some of those individuals may have died of the underlying disease, some may have changed their mind about the manner of their death.

In their study examining the practices that surround euthanasia, Dutch and American researchers found that euthanasia discussions with patients, “in part serve a palliative effect, affirming social bonds and social identity at the end of life, and putting the onus on patients to continue discussions towards a euthanasia death”³⁸. This open approach to discussions on dying and a willingness to engage with the patient may also contribute to a personal sense of control in the dying process.

Whilst it can be plausibly claimed that some of our participants may change their mind (about wanting a medically assisted death) as their future fears are not realised, or are successfully managed by other means, we cannot assume their current reasons for supporting medical assistance to hasten death will not have implications for their future medical treatment and care. This is an area of end of life decision-making that requires further research.

Whilst the findings of our study are not intended to be generalisable, they contribute to a wider body of knowledge around the influences and attitudes of personal preferences in regards to medical treatment and care at the end of life.

These findings highlight the need for health care practitioners to be aware of, and attentive to, the multifaceted reasons some healthy older individuals may have towards medical treatment and care at the end of life, especially where an individual expresses a desire to withdraw or withhold certain medical treatments.

Fear of losing one's independence and becoming dependent on others as one ages appears instrumental in influencing and shaping preferences made near the end of life. Although dependence on others is an essential feature of human development, and an essential condition of what it is to be a human person²⁹ some participants seemed to view dependency as deficiency; almost as though the loss of independence was a failure on their part.

Seale and Addington-Hall³⁹ found in their study which described the circumstances in which a representative sample of adults died, that certain forms of distress and dependency are more likely to lead to desires to die sooner, and to requests for euthanasia than others.

Prior experiences with health care that have involved the dying and death of a family member or friend may also deeply influence an individual's expectations of medical treatment and care available at the end of life and what they may want at the end of life. It was clear from several participants that the health practices they witnessed and often experienced (sometimes decades ago) would not be practiced today.

Informing older patients about advances in certain medical treatments and life expectancy outcomes may assist in alleviating concerns and fears around end of life issues. Inviting older patients to discuss such experiences may encourage dialogue around issues of dependency, the management of pain, and fears of becoming a burden on others.

As for study limitations it is important to note that all our participants identified as being of European descent. Thus we were unable to explore some of the particular issues of significance that may have arisen in the context of end of life decision-making for people who may have very different outlooks around dying and death. For instance, in communities where members have a more collectivist approach towards how decisions are made across the life span (as opposed to more individualistic approaches), support for medical hastening of death may be viewed very differently.

In an American study, Cahill and colleagues found that White older adults were more likely than Black older adults to discuss burden⁴⁰. They concluded that the expression and meaning of burden differed according to ethnicity; "burden is expressed in different ways and meanings that sometimes correspond to the experiences of particular ethnic groups".

Exploring the reasons other groups of individuals have for supporting medical assistance in hastening death will add to a more nuanced picture of how end of life decision-making is approached and shaped. This should include individuals who live with chronic conditions, diverse ethnic groups, those who are disabled, younger

individuals, and those who hold spiritual or religious beliefs that inform their decision-making.

We are currently undertaking a qualitative study that is exploring the reasons some healthy, older individuals oppose medical practices that hasten death. There is a scarcity of research exploring and understanding the issues arising for different groups of individuals near the end of life within the context of hastening death.

Furthermore the problem of dependency needs to be addressed at a deeper level than we were able to go in this study. Seale et al,³⁹ note that “*the issue of dependency in the elderly is a broad one, and may not be as amenable to remedy as certain symptoms have proved to be*”.

Although surveys from many different countries indicate that increasing numbers of the public support medical assistance in hastening death, we still know very little about their reasons for doing so. We believe it is crucial to understand the reasons why people support medical practices that hasten death well in advance of such practices ever becoming legally available.

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Competing interests: PJM is a member of Voluntary Euthanasia Society of New Zealand (VESNZ), an organisation that supports legal medical assistance in dying. The rest of the research team (KM and MJ) are not. PJM did not interview any of the participants and only had access to anonymised transcripts.

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