

# Cracking open death: death conversations in primary care

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## ABSTRACT

**INTRODUCTION:** Research supports talking about death outside the end-of-life context. Benefits include allaying death anxiety to increased engagement in health promotion interventions. Nonetheless, the focus on death conversations remains centred on the imminently dying. This qualitative study investigated New Zealanders' perspectives on the value of, opportunities for, and barriers to death conversations in primary healthcare.

**METHODS:** Twenty-one participants were interviewed. Participants were young older adults (54–65 years) not receiving palliative care or diagnosed with a terminal illness. Most were women who identified ethnically as New Zealand European. An immersion–crystallisation approach to thematic development was used to accommodate the multidisciplinary research framework.

**RESULTS:** Four core themes were identified: 'a need to talk about death'; 'the role of the GP'; 'broaching the topic'; and 'media'.

**CONCLUSION:** A cultural silence on death has rendered both the medical and lay community insufficiently prepared for frank and meaningful engagement with the topic, exacerbated by restricted consultation timeframes. The ease of death conversations may be facilitated by taking a family-centred approach, using community organisations and settings, and harnessing conversation entry points provided by the media. Future research should aim to develop tailored resources and frameworks to support general practitioners' meaningful engagement with the topic of death both within and outside of the end-of-life context.

**KEYWORDS:** Death conversations; general practice; death taboo; mortality; patient-centred medicine

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## Introduction

'Though the fact, the physicality, of death destroys us, the idea of death may save us.'<sup>1</sup>

'I don't understand why we can't talk about [death] because it's just the flip side of birth. And people can't wait to talk to you when you're pregnant, people can't wait for every little bit of detail.' [June, interview participant]

General practice in New Zealand has suffered encroachments on the traditional cradle-to-

grave model of care over the last two decades, with steadily diminishing involvement in the beginnings and endings of life.<sup>2–5</sup> Yet general practitioners (GPs), particularly GPs working in small and rural areas, remain grounded in the communities they serve, attuned to the flux of their patients' life course. They are well placed to engage with sensitive issues such as death, based on the foundation of relationships built on trust that have developed over time.<sup>6</sup>

There is broad recognition of the need to crack open the topic of death,<sup>7–9</sup> to challenge the death-

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## WHAT GAP THIS FILLS

**What is already known:** The need to ‘crack open death’ as a topic of conversation in the primary health care setting has previously been acknowledged, and general practitioners appear well placed to raise this sensitive issue. Despite this, the focus on death conversations remains largely in the context of end of life care.

**What this study adds:** This study identifies some complexities that surround death conversations from a patient perspective. Death conversations are considered within the purview of general practice but lack of preparedness for them was identified in both the lay and medical community.

denying culture that seems convinced that an endless supply of life-prolonging health is available, at a price.<sup>7,10–13</sup> Perceived benefits of removing the cultural silence on death and dying are considered far-reaching: reduced death-related anxiety and increased acceptance of mortality;<sup>14,15</sup> increased knowledge, documentation and stability of end-of-life care wishes;<sup>16,17</sup> increased engagement with palliative services and reduced hospitalisation;<sup>17</sup> and increased engagement with health promotion interventions.<sup>18</sup> Disadvantages are that death conversations are resource intensive, there may be fear of diminishing or

extinguishing hope, and unwillingness to engage on the part of both doctors and patients.<sup>19</sup>

Despite these acknowledgments that conversations about death are important for all people – regardless of age and state of health – the focus on death conversations remains centred on the imminently dying and sequestered within the context of advance care planning.<sup>20–22</sup> Cotton argued that death conversations should be viewed as routine and as important as blood-pressure checks.<sup>23</sup> More recent research affirms that many patients find the topic of death acceptable and a platform for discussing disease risk and health promoting behaviours;<sup>24,25</sup> the conversation simply needs to be tailored to the individual.<sup>23,24</sup> Two fundamental aspects of general practice in New Zealand enable clinicians to provide such personalised care: a patient-centred approach and continuity of care.<sup>26</sup>

The research presented in this paper is part of a preliminary investigation into New Zealanders’ expectations of the time and cause of their own death, and how these influence health behaviours. Specifically, the study scrutinised the role of GPs and explored implications for practice. This paper describes and discusses these implications.

## Methods

The target population was young older adults (54–65 years) who were not receiving palliative care and had not been diagnosed with a terminal illness where death was expected within the following 12-month period. Twenty-one participants living in the greater Dunedin region were recruited following the recruitment pathway described in Table 1. Ethics approval was obtained from the University Ethics Committee (Health) (H14/144).

An interview schedule was developed following three practice interviews. Flexible questions were framed around three core areas: reflections on aging and death; openness to, current engagement in, and influences on death conversations; relationship between death and health behaviours. Interviews were held in participants’ choice of venue and were digitally recorded,

Table 1. Summary of participant’s demographic and recruitment data (n = 21)

<b>Sex</b>	Female	15
	Male	6
<b>Ethnicity</b>	NZ European	9
	Samoan	1
	Tokelauan	1
	Malaysian Chinese	1
	South African	1
	Canadian	1
	British	1
	<b>Recruitment pathway</b>	General practice referral
Local newspaper advertisement		7
University newsletter advertisement		9
Friend/colleague referral		3
<b>Place of interview</b>	Personal home	6
	University interview room	9
	Workplace office	6

Data are presented as n.

transcribed verbatim and member-checked, then circulated among the research team for feedback and ongoing direction regarding the data collection process.

The analytic approach was immersion–crystallisation, a method suited to phenomenological research concerning lived experience and a multidisciplinary approach (our research team drew on expertise in anthropology, sociology, public health and general practice).<sup>27–30</sup> Data analysis was conducted on an ongoing basis as each transcript was completed. Two team-wide coding concordance meetings were held. The first developed a coding framework for thematic analysis. The second discussed the preliminary thematic development, explored alternate interpretations and reached consensus concerning how to report the findings.

The reported findings largely concern the second core research area: openness to, current engagement in, and influences on ‘death conversations’. All names are pseudonyms.

## Results

Four core themes were identified: ‘a need to talk about death’; ‘the role of the GP’; ‘broaching the topic’; and ‘media.’ Each theme is described by subthemes, and further illustrative quotes are contained in Table 2.

### A need to talk about death

#### *Rare and precious opportunity*

Many participants expressed, unprompted, that they were grateful for the process of the interview, in its provision of an opportunity to discuss matters of aging, death and dying. Many participants reported that health professionals should broach the subject of death with patients. The perceived benefits of death conversations were far-reaching: from ensuring one’s end-of-life preferences are upheld, to averting potential conflict between different groups of health professionals, family members and care agencies that may be involved in end-of-life care. Participants viewed discussions around death as a way to normalise death in a

sociocultural environment where death is not as frequent nor familiar as it was for earlier generations, due to improved public health and medicine.

‘People need to talk about it [death] more. I think it’s because it’s such a taboo subject – and it shouldn’t be.’ [Mable]

#### *Inadequately prepared*

Two key issues were raised relating to insufficient preparedness to engage in death conversations. Foremost, various participants felt inadequately prepared to effectively discuss death or provide support to family and friends in need, which they attributed to a cultural reluctance to talk seriously about death. A gap regarding the availability, knowledge of, or prominence of services and resources related to death and dying was identified. Second, the need for more ‘truthful’ death conversations was also raised. Various participants relayed potentially devastating instances where medical professionals had not been forthright about the impending death of relatives. This may be in keeping with the principle of not extinguishing hope. However, the death taboo was seen by participants to be propagated by the medical establishment itself, which is indicative of a societal need to normalise and increase confidence with death conversations.

‘When my mother was in hospital, I had no idea – none of us did – that she was actually dying... It’s sort of like they’re trying to protect you from something that’s very obvious. It must be obvious. Yeah, I don’t think people appreciate having someone try to spare their feelings.’ [Olive]

### GPs’ role

#### *Attitudes and expectations*

Some participants referenced the traditional ‘doctor as expert’ type of relationship and indicated that they had not made lifestyle changes because their doctor had not initiated that advice. While these responses suggest that participants may be willing to follow their doctor’s advice, it also places doctors in the difficult situation of being held responsible for inaction.

Table 2. Thematic framework and indicative quotes

Theme	Subtheme	Indicative quotes
<b>A need to talk about death</b>	<b>Rare and precious opportunity</b>	• Olive: 'It's actually really interesting just to say out loud stuff that you think but never voice. Because why would you? You don't sit down with friends and, 'Let's have a chat about death'. You just don't do it, do you? No.'
		• June: 'Yes, it's been good to talk to someone about it. Because I've had all of this stuff bubbling around in my head and not a lot of outlet for it.'
		• Saul: 'Just to ask people what their attitudes to death are, is valuable in itself because we now live in a society where that's the last question that people want to be asked.'
		• Wendy: 'See now I shouldn't feel unusual for wanting to talk about it, and yet I do. By talking about it with you, you've made me sort of confront myself again. That's another reason why it's good to talk.'
	<b>Inadequately prepared</b>	• Wendy: 'It was really hard to talk to her about death... It was really hard for me to know how to approach her. It was so big for her but it was this big wall, like she was so isolated. It was sort of terrible actually... I had to really get over myself to go and see her and interact with her because it was so much easier to run away from her.'
<b>Role of the General practitioner</b>	<b>Attitudes and expectations</b>	• Barry: 'If I go to a doctor or a medical practitioner, I want to engage in a conversation about my health. If I ask a question, I expect it to be answered...'
		• Angela: 'I like to empower myself with my own health information...'
		• Carrie: 'I think most people tend to have the same GP for an extended period of time, unless of course you move towns. So you build up that relationship with that person just like you do with your hairdresser, if you think about the subjects you touch on when you're getting your hair done.'
		• David: 'I'm sure that where people who are overweight or obese, then they will give the lectures and the talks about what they should do. But I think how it comes across as a lecture or a talk, it's not necessarily to say, 'Look, I want to give you some advice about retirement and how you're going to get through to a ripe old age.' ...Their role is to look after them today. While they should have them to look after for the rest of their life, I don't necessarily think that's top of their agenda. Could be doing them a great disservice.'
		• Marsha: 'I think people could think about are there things I want to tidy up? Are you leaving, with your legacy, are you leaving some things that you are not that happy about? Where you feel that you wronged somebody. Because I know sometimes with people when they get older those things can be... bothering them.'
		• Tracey: 'Do you want partners? That sort of thing. That can make for an interesting question. How does that influence what you do over this next ten years? Am I actively hunting because I don't want to be on my own or... you know?'
		• Tracey: 'Going into 60, my risks go up. Up until now, the last quite a few years, I've just been taking aspirin, but now just in the last six weeks they've put me on to a form of chemotherapy which will bring the platelets down. That's because I turned the magic age of 60. That was like 'Oh! Okay...'
<b>Broaching the topic</b>	<b>Windows of opportunity</b>	• Wei: 'Maybe now that you've asked me question, I might start looking for answers myself.'
		• Tracey: 'And is that what it's called? Advanced care directive? I could Google something like that?'
	<b>Framing the conversation</b>	• Saul: 'It's like saying, 'Oh yeah well I'm becoming old and decrepit, so I'll join an organization for old and decrepit people.' It's like going to reinforce that mindset that you're not coping. I'm sort of being the devil's advocate here because... I think you can over-talk the problems involved with ageing and fence it off as a special area.'
		• Tracey: 'I reckon group talks, like we try and do now and then with our friends. even if the GP says, 'Oh, I'm having a meeting of people in their sixties. Do you want to get together and talk about what you're doing for the next ten years?' That sort of thing. Getting together with people of similar ages.'
	<b>Community pathways</b>	• Henry: 'The body in Christian terms is referred to as the Temple of the Holy Spirit. The body is sacred. I once heard a minister at a Christian mission telling people in Tonga, why they should not smoke. He said your body is a Temple of the Holy Spirit. You should not contaminate it with cancer causing chemicals...They had an ethical dilemma, how do they align their practice with their theology?'
<b>Media</b>	<b>Powerful brokers of social consciousness</b>	• Wei: 'You can't help [thinking about death] if you tend to read the health section in any magazine, newspaper that you come across.'

'I haven't talked to my doctor about [death], no. He hasn't asked. I trust them that they're doing the right thing.' [Karl]

Other participants however, expressed strong expectation to be active and equal players in health management strategies and decision-making. Some participants voiced outright distrust in health professionals, often due to negative past experiences. Lack of faith in the medical establishment appeared to reduce the readiness to seek or adopt advice, while at the same time increasing participants' reliance on self-research and personal risk assessment.

'He [GP] did try to push statins onto me and I refused. There is a point here where I will go and do my own research. I won't just swallow the drugs that are pushed onto me.' [June]

### Future planning

Participants valued the 'cradle-to-grave' model of general practice. The continuity of care afforded by this model was seen to provide the level of intimacy necessary for frank conversations about sensitive issues. Nonetheless, constraints of the current health care system were broadly recognised. Short timeframes of standard GP consultations were seen as a significant constraint to meaningful engagement and discussing issues that at first sight might be outside those pertaining to patients' presenting complaints.

Nonetheless, greater discussion or engagement with 'future planning' was considered desirable by many participants, who advocated for clinicians to prompt reflection on the ageing baby boomer phenomenon. Such future planning was not only concerned with physical aspects of aging and death, but also psycho-socio-spiritual matters. Overall, there appeared to be agreement that 'at the end of the day, growing older and dying is about negotiating relationships' [Barry], and that this should be acknowledged in the clinical setting.

### Broaching the topic

Having established the need to talk about death within consultations, and that the topic lay

within the purview of GPs, various insights were offered by participants about how to initiate death conversations.

### Windows of opportunity

It appeared that various windows of opportunity for death-and-aging-related conversations were not adequately harnessed. The change in Tracey's (Table 2) pharmaceutical regime had sparked significant changes regarding age-related self-perception and the fleeting nature of life, yet the topic of aging and death had not been broached by her doctor. The research interview appeared to provide the first opportunity for some participants to actively reflect on matters of great personal significance, and the consequences of lifestyle decisions.

Aside from capitalising on occasions of significant medical incidents or life-stage transitions, participants wanted clinicians to initiate death conversations of their own accord. As mentioned in the previous theme, deference to medical practitioners for health management guidance, prompting and monitoring was commonly expressed on the grounds of trust and limited personal medical knowledge.

'My husband has psoriatic arthritis. I don't know how he's going to go in the future. He might not be able to work... That would be quite a good thing for doctors to initiate [a family-based consultation to discuss the future].' [Heather]

The power of prompting was indicated throughout the interview process. Following discussion of end-of-life care, some participants conveyed their intention to complete an advanced care directive and initiate conversations with family members. The ability of the health care setting itself to provide opportunities for the development of death awareness or consciousness was also suggested, such as the availability of 'death and dying' information or guidebooks in doctors' surgeries. Further, there may be an opportunity for another health care professional, nurse or counsellor to explore these death issues with relevant patients and family members.

### Framing the conversation

The framing required to ensure meaningful engagement with the topic of death appeared to be highly variable, and dependent on individuals' self-perception regarding age and state of health. Overall, participants suggested that death conversations be framed within needs and risk assessment frameworks for each patient.

Taking a wellness- and family-centred approach was suggested by some as a way to engender comfort with the issue. Various benefits were perceived to flow from the involvement of family members in clinician-led death conversations. These included increased willingness to talk about sensitive issues due to the involvement of an unbiased, authoritative third party; more serious consideration of and adherence to health advice; increased sustainability of health management changes due to increased family understanding of and involvement in these changes.

'I think that a [family-based consultation] would be the sort of thing that [husband] would be more likely to respond to, because a GP is a professional.'  
[Winona]

### Community pathways

Reference was also made to alternate settings to instigate death conversations, such as religious organisations, volunteer groups and workplaces. These three groups were considered to be potentially powerful brokers between individuals and primary health care.

'It was at the fire brigade because they had a yearly check-up... Yeah, that the blood pressure wasn't right. 'You need to go and see the doctor,' 'okay.'  
[Karl]

## Media

### Powerful brokers of social consciousness

Participants referred to the media as a significant source of health-related information that guided health management strategies and general perspectives on death and aging. The media was able

to prompt death planning or consideration; the power of funeral advertisements was cited, having sparked some participants to initiate family conversations about end-of-life care. The power of the media was also notable in that nearly all participants raised the issue of euthanasia and appeared to be engaged – to varying degrees – in the public euthanasia debate taking place in New Zealand at the time of interviews. Participants considered the media a powerful tool to break both the 'death taboo' and the general silence on what many felt was still perceived to be an 'undesirable' or 'uncomfortable' conversation.

'I think it's spoken about more even in a subtle way on the telly and stuff. You've got that ad about funeral cover and the funny thing is, if you're over 55... you're automatically accepted. I remember thinking, 'oh my God, it means I'm in the range, I'm in the zone for this,' which is a little scary.'  
[Carrie]

## Discussion

This research adds to a small body of literature affirming the need for 'death conversations' in primary care. The semi-structured interviews provided valuable insights regarding the value of, opportunities for and barriers to death conversations in this setting. Participants expressed gratitude to the interviewer for the opportunity to discuss death and dying. A cultural silence on death was perceived to have rendered both the medical and lay community insufficiently prepared for frank and meaningful engagement with the topic. Death conversations were considered well within the purview of general practice, although tensions were perceived regarding timeframes for meaningful engagement.

Nonetheless, continuity of care in general practice provided ongoing opportunities and the necessary foundation of trust and personal intimacy, to raise the topic of death. Participants provided insights regarding the need for individualised 'framing' of death conversations, the value of a family-centred approach, and the potential for community settings to provide useful windows of opportunity for death conversations. The American Bar Association's Commission on Law and Aging suggests that opportunities for

advanced care planning arise with deaths of family members and friends, divorce, new diagnoses, significant declines in health, or when people reach a new decade of life.<sup>31</sup> We suggest that these life events also offer windows of opportunity for GPs to initiate death conversations with patients.

The present findings support existing literature identifying a culture shift regarding death preparation in medical professionals.<sup>8</sup> The advance care planning literature provides insight into barriers for meaningful engagement with death, from a tendency to avoid the topic and reassure that 'all is well' in situations of serious illness, to lacking the time, skills or general willingness to engage with the issue.<sup>32-35</sup> We support the conclusion by McLennan *et al.* that death conversations fall within the role of health professionals, and that steps need to be taken to ensure death is not 'avoided at personal and professional levels.'<sup>36</sup>

Increased engagement with advance care planning and end-of-life care processes that facilitate increased death conversation preparedness by GPs are currently being rolled out in New Zealand.<sup>37</sup> However, as the article by Cotton points out, death conversations should not be confined to the end of life.<sup>23</sup> Resources for death conversations in the context of advance care planning and hospice care already exist.<sup>38,39</sup> If the experiences and perspectives of our participants reflect those of other New Zealanders, there may be a need for tailored resources that support GPs to engage in death conversations at all stages of age and health. Participants of this study indicated that advance care planning provides a credible point of entry to death conversations, so the promotion of early, iterative advance care planning processes grounded in the elucidation of health values may provide the key for greater engagement with death conversations – outside the end-of-life context – by both medical and lay communities.<sup>16,40</sup>

The 'Respecting Choices' initiative is an international model for early advance care planning.<sup>41,42</sup> 'Respecting Choices' approaches advance care planning as an 'ongoing process of communication' with three formal steps: the 'first step' where advance care planning conversations are personalised to the context of any healthy adult

over the age of 18 years; the 'next step' to address the needs of patients who are experiencing complications with their chronic condition; and a 'last step' for patients having reached the need for end-of-life care. The power of 'Respecting Choices' is its framing of death conversations as pertinent to all individuals, regardless of age and state of health, while at the same time acknowledging its heightened relevance for people experiencing serious medical complications or who are at the end of their lives. National adoption of such an early iterative process, we expect, would provide a simple strategic framework for GPs and other health care professionals to engage with the topic of death, enhancing their preparedness and willingness to 'crack open' the subject with patients of all ages.

Harnessing the various entry points provided by the media may also facilitate death conversations in consultations, particularly when patients with whom GPs would like to have these conversations are reluctant to engage. The availability of such entry points was evidenced by unprompted reference to the widely reported Lecretia Seales euthanasia court case in New Zealand by nearly all participants, and the popularised Longevity Explorer Ubble Test ([www.ubble.co.uk/](http://www.ubble.co.uk/)), which offers an indication of relative against actual age.<sup>43,44</sup> The recent rise of 'death' as a topic of exploration in the media can be seen to signal – as our participants affirmed – that there may be a need for greater engagement in death conversations in primary care.

In light of the small and mostly self-selected participant sample, insights drawn from the interviews are necessarily tentative. This paper provides insight into patients' perspectives of talking about death outside of end-of-life care. If progress on cracking open the cultural silence on death is to be achieved, research into doctors' perspectives on death conversations also is necessary. We suggest three key areas for investigation: what are the attitudes of GPs towards death conversations?; what resources and frameworks can be made more salient and accessible to assist death conversations in primary care?; and how can GPs use community settings and the media towards the goal of meaningful engagement around the topic of death? The authors propose a

study using a nationally representative sample of both doctors and patients to shed light on these questions, and further elucidate the potential of death conversations to increase engagement with death-and-aging-related, health-promoting behaviours.

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#### COMPETING INTERESTS

None.