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“It was peaceful, it was beautiful”. Family descriptions of good end of life care in hospital for people dying in advanced age

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Complete List of Authors:	Gott, Merryn; University of Auckland, School of Nursing Robinson, Jackie; University of Auckland, School of Nursing Moeke-Maxwell, Tess; University of Auckland, School of Nursing Williams, Lisa; The University of Auckland, School of Nursing Black, Stella; University of Auckland, School of Nursing Wharemate, Rawiri; University of Auckland, School of Nursing Wiles, Janine; University of Auckland, School of Population Health
Keywords:	Hospitals, Aged, 80 and over, Palliative care, Public health, Indigenous populations, Caregivers, Family-staff relations
Abstract:	<p>Background: Hospitals are important sites of end-of-life care, particularly for older people. A need has been identified to understand best practice in hospital end-of-life care from the service user perspective.</p> <p>Aim: To identify examples of good care received in the hospital setting during the last three months of life for people dying in advanced age from the perspective of bereaved family members.</p> <p>Design: A social constructionist framework underpinned a qualitative research design. Data were analysed thematically drawing on an appreciative enquiry framework.</p> <p>Setting/Participants: Interviews were conducted with 58 bereaved family carers nominated by 52 people aged >80 years participating in a longitudinal study of ageing. Data were analysed for the 21/34 cases where family members were 'extremely' or 'very' satisfied with a public hospital admission their older relative experienced in their last three months of life.</p> <p>Results: Participants' accounts of good care aligned with Dewar and Nolan's relation-centred compassionate care model: 1) A relationship based on empathy; 2) Effective interactions between patients/families and staff; 3) Contextualised knowledge of the patient/family; and 4) Patients/families being active participants in care. We extended the model to the bicultural context of Aotearoa, New Zealand.</p> <p>Conclusions: We identify concrete actions that clinicians working in acute</p>

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	hospitals can integrate into their practice to deliver end-of-life care with which families are highly satisfied. Further research is required to support the implementation of the relation-centred compassionate care model within hospitals, with suitable adaptations for local context, and explore the subsequent impact upon patients, families and staff.

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Manuscripts

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3 **Title: “It was peaceful, it was beautiful”. Family descriptions of good end of life**
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6 **care in hospital for people dying in advanced age**
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8 *Merryn Gott^{1,2}, Jackie Robinson^{1,2,3}, Tess Moeke-Maxwell^{1,2}, Stella Black^{1,2}, Lisa
9
10 Williams^{1,2}, Rawiri Wharemate², Janine Wiles⁴.
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13
14 **Short Title: Family descriptions of good end of life care in hospital**
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16 ¹ School of Nursing, University of Auckland
17

18 ² Te Ārai Palliative Care and End of Life Research Group, University of Auckland,
19 New Zealand

20 ³ Auckland District Health Board
21

22 ⁴ School of Population Health, University of Auckland
23

24 Corresponding author
25

26 85 Park Road
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28 Grafton, Auckland, 1240
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What is already known about this topic

- Most older people experience a hospital admission in their last year of life and therefore optimising end-of-life care to better meet their needs, and those of their family, is a pressing priority.
- Research to date has focused almost exclusively upon capturing and reporting the negative aspects of patient and family experience of hospital admissions within a palliative care context.

What this paper adds

- Bereaved families are highly satisfied with end-of-life care in hospital when there are empathic interactions between patients/families and staff, where staff draw on contextualised knowledge of the patient and family to provide care, and where patients and families are supported to be active participants in care.
- These components of satisfaction align with Nolan and Dewar's relation-centred compassionate care model, which we extended to the bicultural New Zealand context.

Implications for practice, theory or policy

- We identify concrete actions that clinicians working in acute hospitals can integrate into their practice to deliver end-of-life care with which families are highly satisfied
- These actions, and family narratives relating to reasons for high satisfaction with care, align with Nolan and Dewar's relation-centred compassionate care model.
- Further research is required to support the implementation of the relation-centred compassionate care model within hospitals, with suitable adaptations for local context, and explore the subsequent impact upon patients, families and staff.

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3 **“It was peaceful, it was beautiful”. Family descriptions of good end of life care in**
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5 **hospital for people dying in advanced age**
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10 **Background**
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12 Public hospitals are important providers of end of life care internationally. (1,2)
13
14 However, research to date has focused almost exclusively upon capturing the negative
15 aspects of patient and family experience in hospitals within a palliative care context,
16
17 (3) leading to calls to elicit patient and family narratives to illuminate best practice in
18 palliative and end of life care in hospital from the service user perspective. (4) This is
19
20 in line with the recognition that focusing on ‘that which is positive, flourishing and
21
22 life giving in [healthcare] organisations’ (5) is an effective way to identify
23
24 opportunities for quality improvement.
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33 Optimising hospital provision to better meet the end of life care needs of older people
34 is a particularly pressing priority. Most older people will experience a hospital
35 admission in their last year of life (6,7) and, in most resource rich countries, a
36
37 significant proportion of older people die in hospital (8). Family members are key
38
39 care providers for older people and data regarding family perspectives and
40
41 experiences has been successfully used to shape policy and service delivery. (9)
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46 Overall, there is increasing recognition of the need to ensure service improvement is
47
48 both rooted in the experiences of service users and theoretically grounded in models
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50 which align closely with that lived experience. (10)
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55 **Aim**
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3 To identify examples of good care received in the hospital setting during the last three
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5 months of life from the perspective of bereaved family members
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10 **Study Design**

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12 Participants comprised 58 family and whānau (whānau is a Māori term for extended
13
14 family and friends) of 52 people who died in advanced age (defined as >85 years for
15
16 non-Māori and >80 years for Māori in line with differences in life expectancy for
17
18 Māori). They had participated in Te Puāwaitanga o Nga Tapuwae Kia Ora Tonu/ Life
19
20 and Living in Advanced Age longitudinal study (LiLACS NZ) in the Bay of Plenty
21
22 region of New Zealand. (11) Our bereaved family and whānau participants had been
23
24 nominated by the older person to be interviewed about their end of life circumstances
25
26 after their death. (12) Interviewers from the LiLACS NZ study invited participation in
27
28 qualitative interviews.
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35 **Data collection**

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37 Face-to-face, and in two cases telephone or face-time, audio-recorded interviews
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39 lasting 1-2.5 hours, and supported by detailed fieldnotes, were conducted between
40
41 2013 and 2015 in a place of the participant's choosing – typically their home. These
42
43 explored the older person's life, their end-of-life circumstances, and the participants'
44
45 experiences of caring and bereavement. The interview guide was developed following
46
47 pilot work and a review of the relevant literature. A structured questionnaire was also
48
49 developed for the purposes of the study to collect detailed information about use of,
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51 and satisfaction with, health and social care services in the last three months of the
52
53 older person's life. In the six cases where more than one family/whānau member was
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55 recruited for one older person, the questionnaire data from the family/whānau
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3 member who was most involved in care was used for the purposes of analysis.
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5 Research with Māori participants adhered to the bicultural framework of Te Ārai
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7 Palliative Care and End of Life Research Group of which we are members (13) and
8
9 all Māori interviews were conducted by Māori researchers (TMM and SB). Interviews
10
11 with non-Māori participants were conducted by LW, TMM and SB. All interviewers
12
13 were women, experienced in conducting interviews about end-of-life issues, and hold
14
15 a PhD in a health-related field, or are working towards one (SB). Interviewers did not
16
17 have a prior relationship with participants. Te Ārai kaumātua (respected elders)
18
19 provided input into study design and analysis, and Māori community researchers
20
21 facilitated fieldwork. Cultural protocols (mihimihi/formal introductions;
22
23 karakia/prayer and sharing of kai/food) were used. (13) All participants were offered
24
25 the opportunity to participate in a Collaborative Storytelling process where the
26
27 research team used their interview narratives to co-create personalised written stories
28
29 about the older person and their end of life experience. This process served both as a
30
31 means of ‘member checking’ and as a way of creating a ‘taonga’ or treasured
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33 possession for participants. (14) Ethics approval for the study was obtained from the
34
35 University of Auckland Human Participant Ethics Committee (UAHPEC 9686).
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45 **Data analysis**

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47 Thirty-four participating family and whānau carers reported that their older relative
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49 had experienced at least one public hospital admission in their last three months of
50
51 life. Twenty-one reported that they were ‘very’ or ‘extremely’ satisfied with the care
52
53 delivered in hospital (see Table 1). All care comprised ‘generalist’ or ‘primary’
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55 palliative care, with no support from specialist palliative care services reported during
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57 the admissions.
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Critical thematic analysis (15), informed by social constructionist and Kaupapa Māori (16) frameworks, was used to develop a coding frame by the original project team (including MG, JW, TMM, LW and SB). This process involved initial line-by-line coding of four Māori and four non-Māori transcripts to facilitate discussion of coding decisions and to enable the context for decision-making to be made explicit by each team member. The coding frame was subsequently applied to all transcripts with the aid of NVivo with a minimum of two researchers coding each transcript. MG and JR worked with the relevant NVivo codes and original transcripts to further understand the perspectives and experiences of the 21 participants who reported that they were ‘extremely’ or ‘very’ satisfied with the care delivered in the hospital setting. Key characteristics of bereaved family/whānau participants are outlined in Table 2; key characteristics of the deceased older people are outlined in Table 3.

Preliminary analyses identified that the care described by this subset of participants aligned with Dewar and Nolan’s theoretical model of relation-centred compassionate care (see Figure 1). (17) They define ‘compassion’ as “an awareness of another’s feelings, an appreciation of how they are affected by their experiences and interacting with them in a meaningful way” p.1248) and propose that compassion can be understood as having four essential characteristics (Figure 1). We adapted their model to the bicultural context of Aotearoa, New Zealand to enable the model to reflect the cultural values of Māori participants. This process involved initial reflection by our Māori researchers (TMM and SB) and subsequent discussion with our research group senior kaumātua, Mātua Rawiri Wharemate who decided the most suitable title for the model was ‘Kapakapa Manawa’. Kapakapa is defined as ‘to get the heart to throb,

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2
3 pulsate, flutter'. The pulsating of the Manawa (heart of a person) motivates a person
4
5 to energise their heartfelt emotions to enact care practices to support the dying person
6
7 and their family/whānau. We believe these understandings both complement, and
8
9 extend, Dewar and Nolan's theoretical model and, more broadly, Western
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11 understandings of 'compassion'.
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17 This extended model was subsequently used to further explore and categorise
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19 participants' descriptions of their experiences of good end of life care in hospital.
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23 **Findings**

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25 The twenty-one participants who reported that they were very or extremely satisfied
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27 with the hospital care their dying older relative received were asked to discuss the
28
29 reason for their answer. All these participants evidenced their satisfaction with
30
31 examples which aligned with the four components of relationship-centred
32
33 compassionate care' or 'Kapakapa Manawa' described in Figure 1. The behaviours
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35 demonstrated by staff and described by participants were not time or resource
36
37 intensive, but contributed substantially to participants' satisfaction with the care they
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39 received. Quotations have been selected to support our analysis: all names used are
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41 pseudonyms.
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49 **Figure 1 here**
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A relationship based on empathy: He ngākau aroha

Participants described how staff demonstrated empathy and provided emotional support to participants during periods of distress, for example when they were being told about their relative's poor prognosis. They felt that staff demonstrated caring for both the older person and themselves through taking time, speaking kindly, and demonstrating their concern for them. For instance, going out of their way to show they care:

Participant: The doctor took me for a cup of tea, and he said "is there anyone you want to call because your father's not going to make it? And I said "oh my son and daughter", and he said "he won't get here in time" and that was when we suddenly realised that it was really serious. When they said "he's not going to get better", I thought they were talking weeks that he would be in hospital and gradually; I didn't realise they meant that day.

Interviewer: Then you did [realise] all of a sudden; but the doctor took you for a cup of tea? That was lovely

Participant: He took me to the lounge and they had a machine there, he was lovely, he was nice (non-Māori daughter for non-Māori father).

The same participant reported that staff using physical contact to provide comfort was also valued:

I can remember when he had had this turn and they took me down to the lounge again and the nurse came to get me to take me back to where they had put him, they moved him to this other room by then and she was putting her arms around me and cuddling me, I can remember that because that's just what I needed.

Considerate behaviour by staff not directly caring for the older person, but in their vicinity, was also mentioned as important. One participant, for example, remarked that:

The nursing care at that time at [the] hospital was compassionate, and dignified and quiet. I use that word because often you go and you can hear these nurses blah, blah, blah, blah out in the corridors, their own stuff whatever. That wasn't like that at all and I appreciated that. (Non-Māori woman for non-Māori friend)

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6 Personal gestures and meaningful rituals and practices at the time of death were also
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8 seen as demonstrations of caring by participants. For example, several family and
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10 whānau participants reported that nursing staff had placed a flower on their older
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12 relative after they had died, which was highly valued by carers. Also valued were
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14 staff who were considered to have 'gone out of their way' to ask how they were
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16 feeling after the death, for example by contacting them the day after the death by
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18 telephone.
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23 **Effective interactions between participants, over time and across settings:**

24 **Whakawhanaungatanga**

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26 Participants valued clinicians who made an effort to build relationships with their
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28 older relatives and themselves. Nurses were identified as particularly well placed to
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30 develop relationships and to 'get to know' them. Several examples were provided of
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32 relatives feeling as if they were 'known', even during relatively short admissions.
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38 The manner of sometimes doctors - they're coming in, they've got a clipboard
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40 and they've got a million patients to see in one time and they're busy and it's
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42 not as if they've spent the day before with [Sam], they don't know me, whereas
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44 the nurses did, and we got to know them really well. (Non-Māori niece of non-
45
46 Māori uncle)

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48 Participants also reflected positively upon staff who acknowledged the personhood of
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50 the older person and communicated with them directly, even when they had
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52 communication difficulties resulting, for example, from hearing or cognitive
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54 impairments.
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57 **Contextualised knowledge of the patient and family: Te taukiri o ngā tangata**

58 **Māori**

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3 Participants felt satisfied with care that demonstrated an understanding the individual
4 and their unique needs. In particular, attempts to understand, and respond to, needs
5 relating to their cultural identity, were valued. One (non-Māori) participant, for
6 example, talked about the excellent cultural care his Māori partner received before she
7 died:
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15 ...when Ana was very low they sang karakia waiata (hymns) and karakia and
16 said prayers; and now Ana didn't ask for it but she really liked that, because
17 you see the last week of her life, she used to get me to bring cold iced water
18 and she used to say "I wish I was out of this hospital. I would love to get into a
19 cold, cold pool, that's an old Māori way, that's what I feel I'd like to do". I
20 used to have to take in this iced water and put a pad and put it on her forehead
21 and she got great relief with that. She seemed to be thinking a lot in terms of
22 Māori traditions and culture, and so when this family came in and people were
23 with her that was good for her. (Non-Māori husband of Māori wife)
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28 Clinical staff acknowledging the personhood of the older person and those close to
29 them was also seen as important. For example, one participant talked about their
30 satisfaction with how the medical team had included important friends in discussions
31 where "bad news" was shared:
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37 I guess they wanted to tell the rest of the family and Podge together, so we
38 were all there together and to try and get Podge to understand what it meant,
39 but she sort of almost knew within herself it was coming up. I was very
40 impressed with the way it was dealt with and the way he handled it personally
41 as well. (Non-Māori friend for Māori woman)
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46 **Staff, patients and families being active participants in their care: Manaakitanga**

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48 Participants responded positively to experiences of being asked to help with caring for
49 their family member, as exemplified by this daughter's response to being invited to
50 accompany her mother for an x-ray:
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56 It was great, it felt so good, and I got to help because Mum couldn't sit up by
57 then and she was absolutely beside herself with pain, she couldn't sit up by
58 then. I helped sit her up and popped out while we did the pictures and then
59 came back. (Non-Māori daughter of non-Māori mother)
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3 The same participant went on to describe how it felt to be able to use the patient
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5 buzzer to summons help from the nurses as she and her sister sat with her dying
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8 mother.
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10 ...we were sitting here in our comfy chairs and they set me up with the buzzer
11 which was another first. I'd spent many months in [a] hospital situation with
12 Dad. I thought, 'I'm allowed the buzzer!', like it was a novelty, because you're
13 never allowed to touch the buzzer as a visitor. Touching the buzzer as a
14 visitor is like so frowned upon. And I got the buzzer and we got to sit there;
15 the nurse [said] "anything happens, you're concerned about anything, or
16 whatever, you push the buzzer".
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20 One Māori participant discussed how the staff had understood their whānau's need to
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22 be with, and provide care, for their older dying relative, and ensured they had a large,
23
24 private room which could accommodate them all:
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27 In that single room, we pushed her round there, and then she died the next
28 morning. She wanted to be with the other people and that was, that night was
29 when I slept with her, because I didn't want to sleep in the ward with the other
30 people, it's disruptive to them and their visitors. That's all I wanted - the
31 single room so I could sleep there whenever we want, so we can make a noise
32 if we wanted to. (Māori daughter of a Māori mother)
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36 Some participants also mentioned they were very satisfied with how they had been
37
38 kept informed about their relative's diagnosis and prognosis and, as noted above,
39
40 were pleased when clinical staff made efforts to include their older relative in
41
42 discussions as well where possible. Reaching a shared understanding with clinicians
43
44 about what was happening to their relative was valued. Participants described how
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46 this was sometimes done through doctors drawing pictures, as well as verbal
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48 discussions:
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52 Daughter: The doctor started his description of what was happening, and he
53 got a paper towel out of the dispenser and he started to draw it for me, and he
54 drew me this body and he showed me all the bits, and Mum had a couple of
55 blockages. He drew me this picture ... he said, "well I think they had to do a
56 couple more tests but if it's been blocked for a long time in the small bowel
57 there really wasn't going to be a lot that they could do" (non-Māori daughter
58 for non-Māori mother).
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5 Easily accessible written information booklets about symptoms during dying were
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8 also mentioned as helpful:
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10 Daughter: We had read the brochures on dying and they said the breathing,
11 you would notice a change in the breathing, and she died about two in the
12 afternoon, her breathing was really rattley and very, very laboured and bad.

13 Interviewer: Where did you get the pamphlets from?

14 Daughter: They were sitting outside her door in the hospital
15 (non-Māori daughter for non-Māori mother).
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For Peer Review

Discussion

Main study findings

Hospitals play an integral role in the provision of palliative care (18), but there are reports in the literature of patients and families experiencing hospitals as negative environments in which to die. (3,19) However, in adopting a framework of appreciative enquiry, this study has highlighted that families do experience end of life care in hospital with which they are very satisfied. We interrogated the components of these positive experiences and identified that they are aligned with the four elements of the Dewar and Nolan's (17) model of compassionate relationship-centred care. Our findings confirm that, whilst originally developed in the UK, the model has global applicability, as well as relevance to the end-of-life period.

These four elements have resonance with previous research exploring what patients and families value in terms of end of life care in hospital, including respectful communication and relationships with health professionals which are based on empathy and compassion (20,21). Indeed, patients have reported that experiencing compassion from health professionals has the most impact on feeling cared for. (22)

We believe the framework provides a practical guide for promoting specific actions by staff at the end-of-life perceived by families to represent compassionate care.

Many other approaches to promoting compassionate care argue the need for individual clinicians to evoke a specific emotion to motivate compassionate actions and to involve 'courage' and 'wisdom'.(23) Within the context of busy acute hospitals, operating under increasing workload and with a dominant focus on tasks to be completed to keep patients safe, we believe this is an unrealistic ambition. As

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3 Bivins et al argue, it is also potentially dangerous given the known high levels of
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5 'compassion fatigue' and 'burnout' experienced by staff working in these settings.
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7 (24). Moreover, as Dutton and colleagues have demonstrated, an organisation does
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9 not become compassionate by hiring compassionate individuals; rather "practising
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11 compassion requires a facilitating social architecture promoting norms of trust,
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13 concern and empathy, in which compassion is treated as a collective responsibility,
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15 rooted in well-defined practices across the whole range of staff roles." (24) We argue
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17 that health care staff can learn and be supported to initiate specific actions which
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19 leave patients and families feeling a sense of compassion from those who care for
20
21 them. We provide examples of well-defined practices which hospitals could support,
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23 and which align well with contemporary initiatives in hospitals, or example the
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25 #hellomynameis campaign. (25)
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33 We also extended the model to the bicultural New Zealand context, identifying
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35 alignment with Māori principles of 'Kapakapa Manawa'. This not only demonstrates
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37 the ways in which theoretical models rooted in Western understandings can be
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39 adapted to incorporate the worldviews of other cultural groups; we argue it also adds
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41 to current understandings of compassion. A critical difference in this Māori
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43 conceptualisation of compassion is the foregrounding of the actions to achieve a
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45 compassionate outcome for families at end of life. In explicitly framing compassion
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47 as a verb the onus is placed on these actions, rather than the emotion itself. This
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49 conclusion aligns with a recent discussion paper identifying structural barriers that
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51 inhibit free-flowing compassion in the global North, many of which relate to fears of
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53 litigation and shape clinician behaviour within a hospital setting. The authors argue
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55 that the Global North has much to learn from the Global South in terms of the
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3 conceptualisation, and actualisation, of compassion. Our study confirms this same
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5 argument could be extended to an acknowledgement of the value of learning from
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7 indigenous knowledges. Moreover, engaging with non-Western epistemologies and
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9 knowledge systems is important if models of palliative care are to be flexible enough
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11 to meet the needs of people from diverse cultural backgrounds. (26,27) Our study also
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13 responds to a particular need to elicit the views and experiences of service users from
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15 non-Western dominant cultures regarding palliative and end of life care in hospital.
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21 The actions valued by families themselves were low cost in resource terms. However,
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23 whilst there is evidence that identifying and disseminating positive examples of good
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25 care can influence the way in which health care professionals interact with patients
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27 and families (28), there is evidence that for staff to deliver ‘compassionate care’, they
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29 themselves also need to feel valued and supported by the organisation in which they
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31 work. (29) Indeed, factors such as negative role modelling, staff fatigue and an
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33 environment which focuses on efficiencies have been shown to impact on health
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35 professionals’ ability to consistently demonstrate compassion in their practice. (30)
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37 Therefore, to achieve compassionate care, or ‘Kapakapa Manawa’, will require not
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39 only modifying individual staff behaviours, but more importantly a culture shift
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41 within the organisation itself.
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49 In conclusion, we believe that the bicultural relationship-centred compassionate care
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51 model we have developed from Dewar and Nolan’s earlier work could provide a very
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53 practical guide for promoting the spread of good practice in end of life care across
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55 hospital environments in New Zealand. We also believe it has the potential to provide
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57 a theoretical grounding for practice and policy in other countries and, in particular, the
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3 flexibility for adaptation to different cultural contexts. Ultimately, we agree with
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5 Zamans et al (2018) that, whilst compassion may be hard to argue against, without
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7 being tied to concrete actions of the type we specify 'it runs the risk of being or
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9 becoming a rather fragile set of exhortatory rhetorics'. (31)
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14 **Strengths and weaknesses**

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16
17 This study used rigorous qualitative methods to address a gap in knowledge by
18
19 exploring good end of life care in hospital from the perspective of a family member
20
21 nominated by the deceased older person. We drew on the data to extend the
22
23 theoretical relationship-centred compassionate care model to the bicultural context of
24
25 Aotearoa, New Zealand and situate it within an end-of-life care context. The
26
27 perspective of the person receiving care, was, however, not studied.
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33 **What this study adds**

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35 Compassionate care is a key tenet both of health care and, specifically, palliative care.
36
37 This study identifies concrete actions that clinicians working in acute hospitals can
38
39 integrate into their practice to deliver end-of-life care that is experienced by families
40
41 as compassionate. Further research is required to explore the implementation of the
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43 relationship-centred compassionate care model within acute hospitals and the
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45 subsequent impact this has on patients with palliative care needs and families, the
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47 remainder of the inpatient population, and staff.
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Declaration of competing interests

None declared.

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For Peer Review

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Table 1: Responses to the question: “Overall, how satisfied were you with the care your family member received in the public hospital in the last 3 months of his/her life?”

	Frequency	Percent
Not at all	1	1.7
Somewhat	3	5.1
Moderately	8	13.6
Very	11	18.6
Extremely	10	16.9
Don't know	1	1.7
N/A	18	30.5
Total	52	88.1

Table 2. Deceased family member characteristics

Gender of deceased	
Male	11
Female	10
Ethnicity	
Māori	14
NZ European	7
Who deceased lived with before death	
Alone	6
Spouse/partner	7
W/child (not spouse)	3
W/others (not spouse or children)	5
Description of deceased's home	
Private dwelling/stand-alone house	13
Private unit/apartment – independent	1
Retirement village – villa or own unit	3
Rest home	4
Last illness (day before they died)	
Heart failure	2
Stroke	2
Cancer	6
COPD	1
Other	7
Don't know	3
Where did deceased die	
At own home	1
In whānau/family room in public hospital	4
In another part of a public hospital eg ED or ward	12
In a rest home/private hospital	4

Table 3. Family carer characteristics by gender, age, ethnicity, employment status and relationship to deceased older person

Gender	
Male	4
Female	17
Age	
40-49	1
50-59	4
60-69	10
70-79	4
80-89	2
Ethnicity	
NZ European	17
Māori	4
Employment status	
Fulltime	9
Part time	2
Retired	8
Not in paid	2
Relationship to	
Spouse/partner	5
Son/daughter	12
Son-in-law/daughter-in-	1
Other family	1
Friend/neighbour	1
Other	1

Figure 1: Kapakapa Manawa: Bicultural relation-centred compassionate care model

Dewar and Nolan's essential characteristics	Aotearoa New Zealand bicultural extension	Example actions identified by study participants
A relationship based on empathy, emotional support and efforts to understand and relieve a person's distress, suffering or concerns	<i>He ngākau aroha</i> Relationships that express care, kind heartedness, benevolence, consideration for others, compassion and empathy.	Speaking kindly Taking time Providing refreshments Use of touch Maintaining quiet atmosphere Flowers placed on body Follow up phone call to bereaved family
Effective interactions between participants, over time and across settings	<i>Whakawhanaungatanga</i> The process of establishing good relationships and nurturing ongoing connections by relating well to others	Introducing yourself Acknowledging the personhood of the patient/family Making efforts to communicate including when people have communication difficulties eg cognitive impairment, hearing problems
Contextualised knowledge of the patient and family both individually and as members of a network of relationships	<i>Te taukiri o ngā tangata Māori</i> Professionals use contextualised knowledge of patient and whānau identity to adapt their practice to the person's views on the world (Te Ao Māori), beliefs, spirituality, personality and other important qualities of self and of others (feelings, skills, knowledge, etc).	Make an effort to understand, and accommodate, cultural beliefs and values Involving family/whānau in discussions and decision-making
Staff, patients and families being active participants in their care	<i>Manaakitanga</i> The relationship between peoples (hosts and visitors/guests); the hospitality, support and kindness towards others. A reciprocal process for sharing and caring for one another and showing mutual respect.	Supporting family/whānau to be involved in care tasks Sharing information and involving family in discussions/decision-making

Adapted from Dewar and Nolan (2013)

Standards for Reporting Qualitative Research (SRQR)*

<http://www.equator-network.org/reporting-guidelines/srqr/>

Page no

Title and abstract

<p>Title - Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended</p>	<p>The title is descriptive of the aim of the study. Pg 1</p>
<p>Abstract - Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions</p>	<p>We have followed PM guidelines on the structure of the abstract for original research. Pg 1</p>

Introduction

<p>Problem formulation - Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement</p>	<p>We have provided a clear background to the study and indicate the gap in the international literature it is responding to. Pg 2-3</p>
<p>Purpose or research question - Purpose of the study and specific objectives or questions</p>	<p>The aim of the study is stated on pg 3</p>

Methods

<p>Qualitative approach and research paradigm - Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/ interpretivist) is also recommended; rationale**</p>	<p>The social constructionist paradigm in which the study is situated and methodological approaches are explicit in the manuscript- pg 2-4</p>
<p>Researcher characteristics and reflexivity - Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability</p>	<p>We have addressed research reflexivity explicitly in the methods section Pg 4-6</p>
<p>Context - Setting/site and salient contextual factors; rationale**</p>	<p>The setting and site are contextualized in on Pg 3-4</p>

1 2 3 4 5 6 7 8	Sampling strategy - How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale**	Addressed in the Methods section Pg 3-6
9 10 11 12 13 14 15 16 17 18	Ethical issues pertaining to human subjects - Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	Evidence of ethical approval is documented on Pg4.
19 20 21 22 23 24 25 26 27 28 29 30 31 32 33 34 35	Data collection methods - Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale**	Data collection methods are provided on Pg 4 - 6.
	Data collection instruments and technologies - Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study	Data collection instruments are detailed on Pg 3-4
	Units of study - Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	This is provided on Pg 3-4
	Data processing - Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/de-identification of excerpts	We have outlined the process of data in the context of the methodologies used. 3-4
	Data analysis - Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale**	Data analysis is outlined on Pg 3
	Techniques to enhance trustworthiness - Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale**	The collaborative story telling process is outlined on Pg4

Results/findings

37 38 39 40 41 42 43 44 45 46 47	Synthesis and interpretation - Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	Themes integrated with, and extends, a prior model
	Links to empirical data - Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	The evidence of our findings is linked to excerpts Pg 7-11

Discussion

48 49 50 51 52 53 54 55 56 57 58 59 60	Integration with prior work, implications, transferability, and contribution(s) to the field - Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field	The manuscript discussion summarises the main findings and articulates how the study adds to the international literature. Our
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1 2 3 4 5 6		paper also outlines the implications of this Pg 12-15
7 8 9	Limitations - Trustworthiness and limitations of findings	We have provided a limitations section on Pg 14

Other

12 13 14	Conflicts of interest - Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	
15 16 17 18 19 20 21 22	Funding - Sources of funding and other support; role of funders in data collection, interpretation, and reporting	We have provided a funding declaration and acknowledgements. We have no conflicts of interest to declare.

*The authors created the SRQR by searching the literature to identify guidelines, reporting standards, and critical appraisal criteria for qualitative research; reviewing the reference lists of retrieved sources; and contacting experts to gain feedback. The SRQR aims to improve the transparency of all aspects of qualitative research by providing clear standards for reporting qualitative research.

**The rationale should briefly discuss the justification for choosing that theory, approach, method, or technique rather than other options available, the assumptions and limitations implicit in those choices, and how those choices influence study conclusions and transferability. As appropriate, the rationale for several items might be discussed together.

Reference:

O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. **Standards for reporting qualitative research: a synthesis of recommendations.** *Academic Medicine*, Vol. 89, No. 9 / Sept 2014
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