Developing a meta-understanding of 'human aspects' of providing palliative care

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Abstract

Objectives: Our intention was to develop a meta-understanding of the 'human aspects' of providing palliative care. Integral to developing this meta-understanding was recognising the individuality of people, their varied involvements, situations, understandings, and responses, and the difficulty in stepping back to get a whole view of this while being in the midst of providing palliative care. We intended for this meta-understanding to inform reflections and sense-making conversations related to people's changing situations and diverse needs.
Methods: Using collaborative inquiry, this qualitative research was undertaken 'with' clinicians rather than 'on' them. Our team (*n* = 7) was composed of palliative care clinicians and researchers from a co-located rural health service and university. We explored our personal perceptions and experiences through a series of 12 meetings over 8 months. In addition, through five focus groups, we acccessed perceptions and experiences of 13 purposively sampled participants with a range of roles as carers and/or healthcare providers. Data were dialogically and iteratively interpreted.
Findings: Our meta-understanding of 'human aspects' of providing palliative care, represented diagrammatically in a model, is composed of ATTRIBUTES OF HUMANITY and ACTIONS OF CARING. ATTRIBUTES OF HUMANITY are *death's inevitability, suffering's variability, compassion's dynamic nature*, and *hope's precariousness*. ACTIONS OF CARING include *recognising and responding, aligning expectations, valuing relationships*, and *using resources wisely*. The meta-understanding is a framework to keep multiple complex concepts 'in view' as they interrelate with each other.
Significance of findings: Our meta-understanding, highlighting 'human aspects' of providing palliative care, has scope to embrace complexity, uncertainty, and the interrelatedness of people in the midst of resourcing, requiring, and engaging in palliative care. Questions are posed for this purpose. The non-linear diagrammatic representation of ATTRIBUTES OF HUMANITY and ACTIONS OF CARING facilitates multiple ways of engaging and revisiting palliative care situations or navigating changes within and across them.

Keywords: caring, humanity, palliative care, patient-centred, qualitative research, reflection

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Introduction

This collaborative research was undertaken by clinicians and researchers, working together to deeply understand *human aspects* of providing palliative care. The intention was to develop a meta-understanding. Integral to developing this meta-understanding was recognising the individuality of people, their varied involvements, situations, understandings and responses, and the difficulty in stepping back to get a whole view of this while being in the midst of providing palliative care. Importantly, this meta-understanding is intended to be a flexible framework to inform ongoing reflections and conversations about providing palliative care for those in the midst of it, rather than offering definitive directives on how

to practice. Reflection, as central to providing palliative care, was a key assumption underpinning the purpose of this research.

Throughout the continued development of palliative care, people remain at the core. They are involved in different ways, including resourcing, requiring, and engaging in care. However, with the range of people involved and the nature of palliative care itself, providing palliative care is understandably complex. Text Box 1 presents our interpretation of this complexity. Highlighted is the diversity of systems underpinning palliative care, the individual nature of patients' palliative care needs, and the multiple shapers of people's approaches to providing palliative care.

Evident in our interpretation of this complexity are quantifiable, reproducible elements of providing palliative care, as well as less-quantifiable, subjective elements. Quantifiable, reproducible elements align with organisational strategies for services, models, roles, and evaluations. These elements tend to be the responsibility of those

resourcing care, including those with managerial and administrative responsibilities. Less-quantifiable, subjective elements align with the individual nature of patients' palliative care needs and the multiple shapers of people's approaches to providing palliative care. These elements tend to be intertwined with perceptions and experiences of the people requiring and engaging in palliative care. We view these elements as the 'human aspects' that create and shape the uncertainty that is inherent in palliative care, including through different illness trajectories, individual contexts, personal inclinations, ways of working, understandings, personal qualities, and particularised responses. While acknowledging the need to be aware of the organisational requirements for quantifiable, reproducible elements, we were interested in these less-quantifiable subjective 'human aspects'.

In the literature, 'human aspects' tend to be richly explored in relation to particular 'parts', such as close-up looks at particular aspects or combinations of aspects, for example, suffering,[24] compassion,[37,48]

Text Box 1. Complexity of palliative care as interpreted from the literature (with examples from a range of literature).

Diversity of systems underpinning palliative care, as evidenced by varied:
- *services*, including those aimed at early stages of illness[1] or involving end-of-life care within or beyond specialist palliative care setting;[2]
- *models*, including in relation to elements of service delivery,[3] replicable care,[4] and particular locations[5] including hospicies, specific units within acute hospitals, aged care facilities, primary health care settings, and the dying person's or relative's home in person or *via* telehealth;[6]
- *roles*, including doctors, nurses, social workers, chaplains, mental health professionals,[6,7] speech-language pathologists,[8] physiotherapists,[9] and pharmacists;[10]
- *evaluations*, such as phases of illness,[11] end-of-life pathways,[2,12] patient and family questionnaire,[13,14] and quality-of-life assessments.[15]

Individual nature of patients' palliative care needs, as evidenced by varied:
- *illnesses*: including cancer, organ failure, neurological diseases, and frailty;[5,6,16]
- *illness trajectory*: such as being gradual, intermittent, or rapid functional decline;[17]
- *individual contexts*: including access to services and availability of support networks,[18–20] other conditions requiring consideration, such as dementia[21] and intellectual disability;[22]
- *personal inclinations* influencing responses, perceptions, and needs related to expectations, suffering,[23,24] and hope.[25,26]

Multiple shapers of people's approaches to providing palliative care, as evidenced by varied:
- *ways of working together*: including working within specialist palliative care roles and roles beyond the boundaries of the specialisation,[1,27,28] within multidisciplinary teams working in professional roles and with families[29] or as part of informal care networks;[18,30]
- *understandings of underpinning concepts* evidenced through nuanced terminology related to palliative care;[31–33]
- *conceptualisations of death*, including different interpretations and logistics;[34,35]
- *personal qualities* influencing interactions: including scope for compassion,[36–39] self-care,[40,41] and ways of engaging with patient's suffering[24] and impending death;[42]
- *particularsised responses*, including limitations of fitting into predetermined models of care,[43] variability of individual and familial needs,[44] the impact of multifaceted family dynamics[45] and bureaucracies[30] and potential for technology to dehumanise care[46] and multiple responsibilities for dealing with staff's emotional exhaustion.[47]

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and hope.[49] However, a meta-understanding explicitly encompassing these different parts into a meaningful 'whole view' for people in the daily midst of palliative care's complexity and uncertainty was not readily evident. Inspired by the caution that interactions with patients should not be 'bureaucratic or technical encounters, but creative, singular, exposing human experiences',[50] we propose that a meta-understanding focusing on 'human aspects' of providing palliative care has scope to embrace the complexity and uncertainty, as well as the interrelatedness of the people involved in resourcing, requiring. and engaging in care.

Core to our purpose of developing a meta-understanding is our view that providing palliative care is a human practice. As a human practice, it is informed by different types of knowledge, including propositional (research- and theory-based) and tacit (wisdom- and intuition-based).[51] By developing our meta-understanding, we aimed to enable tacit knowledge to become explicit and able to be reflected upon. Thus, this meta-understanding could provide a 'reference point' for making sense of particular situations during or after the time they are experienced (based on Schön[52]). These may be tricky situations with to scope explore 'what can be done differently', or seamless situations to be understood in order to 'do more of the same' (informed by Whitney and Trosten-Bloom[53]). Implicit in our purpose is our view that reflections and conversations are important for providing palliative care that is responsive to changing situations and diverse needs.

We chose the overarching notions of *humanity* and *caring* as a basis for developing our meta-understanding of 'human aspects' of palliative care. Informed by Higgs and Horsfall,[54] we deliberately chose a noun (humanity) and a verb (caring). Text Box 2 outlines the rationale for our choice of a noun and a verb, and key ideas from literature about *humanity* and *caring* that informed the understandings we brought to the research. Thus, we understand 'humanity' as being important for ensuring that people's interactions are based on respect and responsibility, and we frame 'caring' as indicating what is required and provided through such interactions. Our intention was to develop a meta-understanding of the 'human aspects' of providing palliative care.

Methods

Design
Our question for this qualitative research undertaken in the interpretive research paradigm was: 'In relation to providing palliative care, how can the notions of *humanity* and *caring* be conceptualised?'. The setting for our research was a rural area encompassing different spaces (specialty

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Text Box 2. Key ideas about rationale for choice of verb and noun, and key understandings of *humanity* and *caring* that informed our research.

Italicising the terms *humanity* and *caring* recognises the complexity of the term, its different meanings to different people, and its changing meanings across time and contexts. Below are the meanings informing our research.

Humanity:
- is a noun, and as such is a 'conceptualisation' that signifies something that is 'widely accepted ..., more general' (p. 239);[54]
- is a necessary idea in modern societies, 'where work is highly distributed and people are significantly dependent on one another's capacities, contributions, and cooperation' (p. 176);[55]
- gives meaning to the scientific, technological, and managerial components of health care;[56]
- requires 'personal commitment to the dignity and worth of humans" and "behaving with respect, compassion and integrity' (p. 314);[57]
- involves individuals and collectives, where individual humanity requires that we respect others' individuality and they ours, and social humanity requires that we take responsibility for others and that others take responsibility for us.[55]

Caring:
- is a verb, and as such denotes 'doing' as 'active immediate, particularised and person-based [that represents] experiencing and understanding of being in the midst of the lived experience' (p. 239);[54]
- includes 'everything we do directly to help others to meet their basic needs, develop or sustain their basic capabilities, and alleviate or avoid pain or suffering, in an attentive, responsive and respectful manner' (p. 55);[58]
- requires skills to ensure adequate symptom control, communicate, and develop trust,[13] provide psychological and emotional support,[11] comfort and dignity,[31] and be attentive to individual needs.[14]

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unit, acute hospital, long term care, and community settings), illnesses (advanced cancer and other diseases), and timings (from early to late access), and people in a variety of roles (including specialised palliative care roles, roles where palliative care is part of wider practice, a number of different disciplines and varying involvement of carers). A key value of this diversity and variety in our rural setting was that it enabled us to explore the notions of *humanity* and *caring* in a manner that transcended, to a degree, particular spaces, illnesses, timings, and roles.

Our research team comprised four health professional clinicians from the Hunter New England Local Health District and three health professional researchers from the University of Newcastle Department of Rural Health in Australia. Represented within the research team were a range of roles (specialist care, primary care, and caring roles) across varied settings (including specialist palliative care unit, community, general hospital, private hospital, and residential care). All research team members had a health professional background (medicine, nursing, and physiotherapy). A core team of two health professionals and two researchers provided constant membership and involvement, with other co-researchers' involvement varying according to their availability (particularly related to training rotations of through palliative care) and the stage of research. While our diversity of roles, experience in roles and time in the rural location provided a good source of 'seeing things differently', our common personal attributes of curiosity and concern for people were integral to coherence between method and topic. The co-location of the health service and the university site in this rural setting of the research facilitated the collaboration between the co-researchers, that is, the core of the research approach.

The research was informed by collaborative inquiry (based on Bridges and McGee[59] see Figure 1). Collaborative inquiry enabled the research to be undertaken 'with' clinicians rather than 'on' them. Twelve meetings (ongoing dialogical conversations) between co-researchers were held over 8 months. A minimum of three co-researchers attended each meeting, with the informal communication between meetings informing other meetings. A lens of appreciative inquiry[53] enabled us to explore perspectives of palliative care in an affirming manner to illuminate and build on positives at the core of the current palliative care services.

Data collection

Data collection (beyond the meetings of co-researchers) involved five focus groups held over 3 months. Focus group participants were purposively sampled to include a range of people with involvement as carers, interested community members, and health professionals (or a combination of these). Emails were sent to 'local network key contacts', identified by the research team through local knowledge or local directories. Emails to key contacts explained the research and asked them, if they agreed, to send it on to people in their networks. Networks accessed included health services (public, private, and non-government-funded organisations) and community groups (church groups, service group, and support groups with members involved and/or interested in palliative care). Follow-up emails were sent 2 weeks later. Thirteen participants provided informed written consent to participate in one or two focus group that lasted about 1 hour. Focus groups were led by two co-researchers (KF and AC). Sufficient data were obtained to answer the research question. Data sufficiency was established through data being 'comprehensive enough (depth) to both identify recurrent thematic patterns and to account for discrepant examples (breadth)'.[60]

As shown in Table 1, participants' varied involvements were accessed. Audio-recordings of focus groups were professionally transcribed.

Data interpretation

Data for interpretation was sourced from (1) co-researchers' meetings (audio recordings and notes about co-researchers' perceptions and experiences of palliative care, diagrammatic representations of evolving conceptualisations, and two transcribed audio recordings, selected for closer analysis due to their richness of conceptualisations), and (2) focus groups undertaken with participants. Data interpretation, informed by philosophical hermeneutics,[61] involved a dialogue of questions and answers (with iterative returns to data to engage with new meanings) until a fusion of horizons was reached (where researchers' understandings of parts of the data fused to reach an understanding of the data as a whole). Two
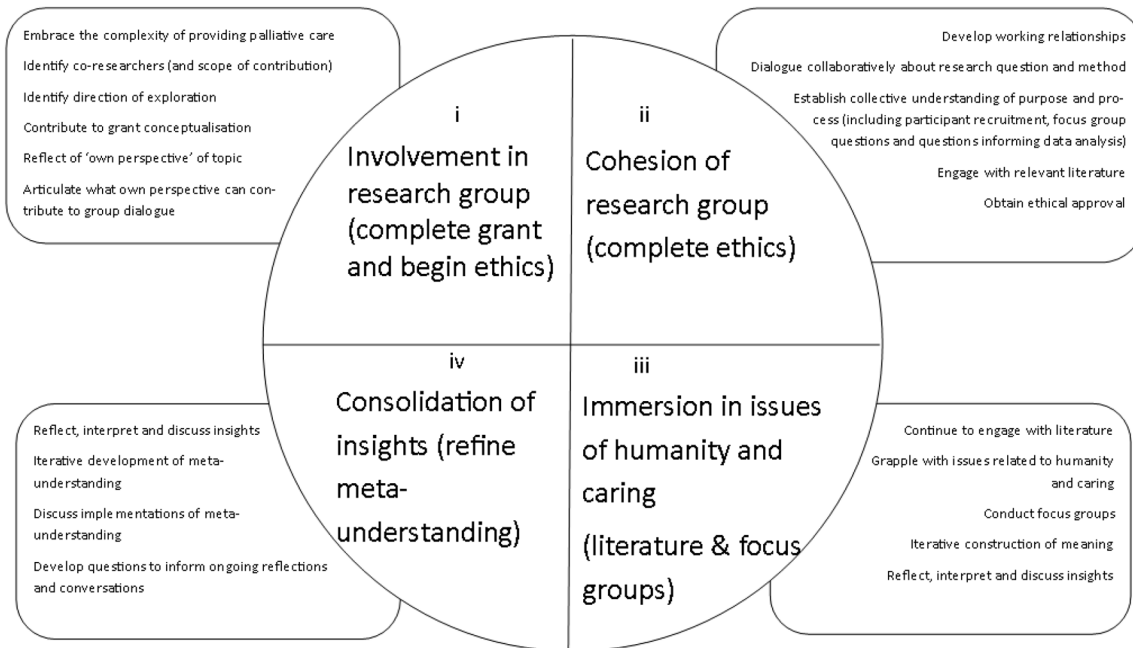
Figure 1. Overview of collaborative inquiry as used in this research (adapted from Bridges and McGee[59]).

co-researchers took primary responsibility for data analysis (KF and AC). Emerging insights and concepts were discussed at co-researchers' meetings. Discrepancies of understanding and sense-making were embraced through rich ongoing discussion. Importantly, discrepancies informed KF's and AC's ongoing question-and-answer dialogue with the data and were resolved by moving insights and concepts to a higher conceptual level. NVivo 12 (https://www.qsrinternational.com/) was used to manage data.

Quality criteria
Quality criteria informing this research were congruence (in relation to the research topic and strategy), authenticity (of researchers interactions in relation to method), and credibility (in relation to research findings).[54]

Ethical considerations
Ethics approval was received from the health service and university (HREC reference no: 17/11/15/4.09). Participants' confidentiality was an important consideration. Participants were requested to maintain the confidentiality of the other participants in their focus group/s in relation to names, roles, and information shared.

Table 1. Participant characteristics.

	Focus groups: initial (3)	Focus groups: follow-up (2)
Gender		
Female	9	5
Male	4	2
Total	13	7
Age		
18–30 years	3	1
31–45 years	2	0
46–60 years	5	4
61+ years	3	2
Total	13	7
Role/s[a]		
As a family member	6	5
As a community member	5	4
As a health professional	7	2

[a]Some participants identified more than one role.

Table 2. Overview of meta-understanding of providing palliative care.

Attributes of humanity	Death's inevitability Suffering's variability Compassion's dynamic nature Hope's precariousness
Actions of caring	Recognising and responding Aligning expectations Valuing relationships Using resources wisely Continuing to reflect

All recorded and transcribed information (data) collected during the research was treated confidentially. The names of research participants were delinked and de-identified from research data. Members of the research team with no clinical roles collected, delinked, and de-identified the data. This ethical consideration was important to prevent the disruption of actual or potential therapeutic relationships. All data and other information collected during the research was kept, and is being kept, on password-protected computers or a locked fining cabinet in a designated 'staff only' area of the university.

Findings
An overview of the findings is presented in Table 2. *Attributes of humanity* were interpreted as *death's inevitability, suffering's variability, compassion's dynamic nature*, and *hope's precariousness*, while *actions of caring* were interpreted as *recognising and responding, aligning expectations, valuing relationships, using resources wisely*, and *continuing to reflect*. The descriptors within the *attributes of humanity* (that is *inevitability, variability, dynamic nature*, and *precariousness*) and the focus on the *actions of caring* (on *expectations, relationships*, and *resources*) are important for capturing the complexity and uncertainty of palliative care situations. Importantly, these notions do not represent a unified narrative of an experience, rather the meta-understanding is a framework to keep multiple complex concepts 'in view' as they interrelate with each other. The brief descriptions of each attribute and action provide 'food for thought' rather than directing how they 'need' to be understood. Quotes from focus group participants illustrate the complexity and uncertainty of palliative care situations and interrelatedness of people resourcing, requiring, and engaging in palliative care. Pseudonyms are used to ensure anonymity.

Participants' roles in palliative care (as a family member, community member, or health professional) are not identified due to attributes and actions transcending particular involvement and some participants being involved in multiples ways. Quotes are chosen for clarity and conciseness, rather than seeking to represent the words of each participant.

Attributes of humanity
The descriptors within the *attributes of humanity* (that is *inevitability, variability, dynamic nature*, and *precariousness*) convey a depth to well-recognised concepts in palliative care (that is *death, suffering, compassion*, and *hope*), thus highlighting complexities and uncertainties of providing palliative care.

Death's inevitability. Death is fundamental to having life. The term 'inevitability' frames death as significant yet universal.

> ... inevitably it [death] is going to happen. (P3)

However, despite its inevitability, death can be difficult to confront, not just for those requiring palliative care but for those with potential to engage in, or refer to, palliative care services. Thus, access to those engaging in palliative care is not necessarily straightforward.

> It's like ... [health profession] can't cope with death. They like to fix people so when they can't fix [they don't know what to do] (P9)

> I think one of the things that even as a ... [health] professional ... it [death] is not just broached, it's not even talked about. (P11)

Suffering's variability. The term 'variability' highlights the individuality and diversity of the suffering experienced by people requiring palliative care. Some aspects of suffering could be readily described by the patient.

> He [the patient] wants to tell me about what's happening with all his suffering. (P7)

Other forms were evident to those engaging in palliative care, without necessarily being explicitly described.

> You'll *hear* pain. [Italics for emphasis] (P13)

I'm sitting there holding the hand of someone who's in desperate pain. (P9)

However, pain was not the only form of suffering recognised.

You have some people who yes, they may be suffering, but they're not suffering with pain ... Pain's only one bit [of suffering]. (P12)

However, caution was expressed for relying on pre-determined expectations of forms of suffering. Openness to each patient's situation was important.

I think break[ing] it up too much into categories of types [of suffering] means that you're in danger of letting the bits fall through the cracks. (P2)

Compassion's dynamic nature. This attribute highlights the importance of considering the personal implications of engaging in care. Although an important attribute of caring, the term 'dynamic nature' recognises that compassion towards others was not a static or infinite resource.

I went home [after caring for the seventh dying patient] and curled up in a little ball in the foetal position and I was like, 'I can't do it anymore'. (P9)

Compassion could be fueled by meaning and purpose, thus enabling people to stretch their caring further than what was easy for them:

I think care fatigue comes into it. But then if you ask me whether I was going to step out of that circle and not care for my parents, that was not an option for me. (P3)

Despite compassion for others and self at times being challenging to maintain, a lack of compassion was not well received.

Please, keep [a particular person who was perceived not to show compassion] away from the patients. (P9)

Hope's precariousness. Hope was not necessarily straightforward and could require careful consideration. For people requiring and engaging in palliative care, the term 'precariousness' emphasises the delicate balance between honesty, expected future directions, and compassion.

Giving people hope when it's not there, is that dangerous? People having a lot of hope when there isn't any hope? You certainly don't want to discourage them but it's not something you really want to support. (P7)

Anticipating the reactions to 'lack of hope' could further complicate this delicate balance.

[One of our young patients] was getting more and more and more unwell ... [but] her parents had told us that we had to tell her ... that there is going to be this magical cure. One night ... she was awake and she said, 'I'm dying. It's not a question ... If I told them [Mum and Dad] that I knew that that [it] would make them sad'. (P3)

Importantly, hope could become less precarious when its focus moved beyond avoiding death.

With death, there's a letting go but I think ... there can be a gaining as well ... Being able to see the person as a whole person and for instance that reconciliation, being able to come to terms with things, can be a gain. There's wholeness to the person before death. (P11)

Actions of caring

Interpreting the actions of caring as verbs (that is *recognising and responding, aligning, valuing, using* and *continuing*) with an explicit focus (that is *relationships, expectations*, and *resources*) highlights the fluidity and versatility required for working within the complexities and uncertainties of providing palliative care.

Recognising and responding. Caring involves *recognising and responding* to the nuanced situations arising from the above *attributes of humanity.*

For example, recognising and responding to *death's inevitability* could enable important dialogues between people who require and engage in care:

Coming in with that soft but firm honesty [about death] gives permission for people to talk to you. Because unless you do it, people won't talk ... You've got to open it up so that they've got permission to do that, so they have that ability. (P3)

Recognising and responding to *sufferings' variability* involved being open to people's varied requirements across different situations.

Because [managing suffering] is quite often [through] the conversation ... It's not [just] pain. ...

So how are you going to enhance their quality of life? By pain management [and] by addressing the things that they're afraid of. (P8)

So we need somebody ... you can ring [urgently] and say, 'Look we need a script, we need *something*' [italics for emphasis]. (P10)

Similarly, recognising and responding to *compassion's vulnerability* was not a one-size-fits-all approach and required sensitivity to the person and requirements of the situation.

He [my husband] made me a cuppa [when I was struggling with my caring role] and was really sweet at first and then he went, 'This isn't about you, and your job is to see them out. Are you doing your job well?' 'Yes'. (P9)

Recognising and responding to *hope's precariousness* is tied closely to aligning expectations, thus highlighting the inter-linking of the caring actions.

So [being able to say] ... to people, 'You'll actually benefit from being around a death'. The life experience you learn ... it makes you [as a person] so rich to be part of [it]. (P5)

Aligning expectations. At times, those engaging in care were not 'on the same page' as each other. When this caring action is absent, its importance is highlighted.

I've often had to pick up the pieces of what a [particular profession] has just said to a patient and the way they've said it to that patient. Here I am picking up the pieces because a patient has a certain expectation, the [particular] profession has another expectation. (P10)

Non-aligned expectations could elicit strong emotions and lead to unanticipated situations.

[My sister marched] into the room saying, 'Get my father out of [the palliative care ward]. He's not dying. What the hell do you think you're doing?' So people have different ways of coping at that stage, so [previously] happy families might be different tomorrow. (P3)

Valuing relationships. Meaningful interactions between people who require palliative care and those engage in care was important. Seeing the patient as a person was core to developing or maintaining such interactions.

It's really important to them [patients] that they're not just a body that needs treatment but they're more than that, they're a person. And if you're being treated as just a body it can be quite alienating. (P2)

The scope for interacting and building relationships beyond those receiving care was recognised as important.

Often we're then talking to the families as well, to the husbands or wives, etc. (P5)

However, due to the multiple roles in palliative care, relationships between those engaging in care might also need to be chosen wisely.

So it's choosing the people [with whom to build meaningful relationships] as well ... I sometimes think ... there's too many cooks ... It's about [the right people] forming those relationships (P3)

Using resources wisely. Beyond the obviously intended wise use of material resources (the availability of which is dependent on those who provide resources) was recognition of time, space, and emotions as resources, and valuing capability to use them appropriately, as shown in the following examples:

She just needed some time where she could just process it [the inevitability of her death], so as well as having people around, you need to know when not to [be around]. (P9)

Wrapping that message in professional warmth ... [palliative care] was just done beautifully ... we were given plenty of space ... I think that was what helped get those two over the line (P3)

Finally, the action of *continuing to reflect* arises from the interrelatedness and interdependence of *attributes of humanity* and *actions of caring*, and for the importance of considering them in an ongoing iterative manner. While not illustrated with direct quotes, we interpreted this action as important for keeping the attributes and actions 'in view' of one another to enable engagement with their shifting 'whole'. The action of *continuing to reflect* informed the development of diagrammatic representation of our meta-understanding, as shown in Figure 2, where the *attributes of humanity* and *actions of caring* are conceptualised in relation to each other.

Importantly, this diagrammatic representation 'begins' and 'ends' with actions. Rather than
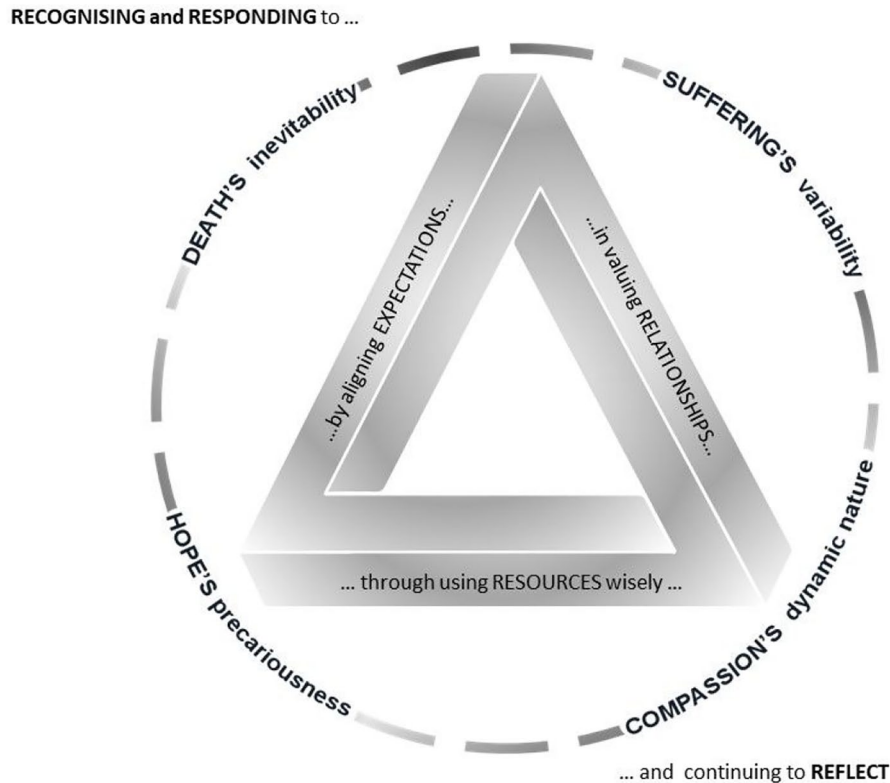
Figure 2. Diagrammatic representation of our meta-understanding of 'human aspects' of providing palliative care.

indicating a linear pathway for considering *attributes of humanity* and *actions of caring* (as implied by the list-like overview provided in Table 2), the meta-understanding provides scope to take multiple and iterative pathways that begin with the action of *recognising and responding* and are fueled by *continuing to reflect.*

Discussion

Our meta-understanding highlighting 'human aspects' of providing palliative care has scope to embrace complexity, uncertainty, and the interrelatedness of people resourcing, requiring, and engaging in palliative care. Not surprisingly, particular elements of our meta-understanding resonate with palliative care literature and can inform 'up-close' considerations of particular 'parts': for example, in relation to authors' explicit considerations of death,[34,62,63] hope,[64,65] compassion,[36,38,48,49,56] suffering,[24,37] resources,[66] expectations,[30,45,49] and relationships.[67,68] However, beyond these considerations of the 'parts', literature can also enrich considerations of the 'whole' of the meta-understanding and deepen understandings of reflective approaches to

the 'human aspects' of providing palliative care. Kenneth Gergen's *relational humanism*[69] and Theordore Schatzki's *bundles of practice and material arrangements*[70] are examples of conceptual schemas that provide theoretical foundations for engaging with the 'whole' meta-understanding interpreted in this research.

Gergen's social construction notion of *relational humanism*[69] provides a theoretical foundation for reflecting on the interplay of *attributes of humanity, actions of caring*, and the people involved. Through reconstructing 'experience, agency, and human understanding' as 'highly relational rather than individualistic' and framing 'meaning as emerging from the process of co-action'[69] (p162), Gergen proposes that 'the site of human meaning is not within the minds of single individuals, but issues from the relational process' (p. 156). This proposition supports ongoing reflection and conversations about complexities and uncertainties in relation to the interrelatedness of people requiring, resourcing, and engaging in palliative care. Thus, providing palliative care can be informed by considerations of different perspectives and

multiple sharing of reflected upon ideas and insights.

Schatzki's concept of *bundles of practice and material arrangements*[70] provides a theoretical approach to embrace the complexity of interrelatedness of people resourcing care and those requiring and engaging in care. He contends that 'the activities that compose practices are inevitably, and often essentially, bound up with material entities' (p. 16), cautioning that this 'labyrinth of linked practices and arrangements' (p. 21) can assume a life of its own and 'unfold in unforeseen ways' (p. 23). This contention and caution highlight the importance of being critically aware of the material arrangements that 'ubiquitously prefigure the perpetuation of practices' (p. 17). Material arrangements are at the core of services, models of care, roles, evaluations, network supports, access, and technology (see Text Box 1). Such critical awareness is particularly important for balancing the influence of quantifiable, reproducible elements of providing palliative care with the less-quantifiable, subjective elements made explicit in our meta-understanding highlighting 'human aspects' of providing palliative care. While both are important, it can be easy to focus on resourcing what can be measured rather than what is experienced.

Importantly for the transferability of our research to other contexts, and in accordance with relational humanism, is our intention not to 'tell people what to do' but rather invite them to use our understanding as a beginning point for their own reflections and conversations about providing palliative care in their own contexts. Similarly, there is no 'right way' or 'right order' for using the model. Our non-linear diagrammatic representation facilitates multiple ways of engaging and revisiting the *attributes of humanity* and *actions of caring* for different palliative care situations or navigating changes within and across them. Key to the model's use is scope to grapple with differing emphases on what people perceive may be important about resourcing, requiring, and engaging in palliative care in particular situations. In Text Box 3 are suggested questions for exploring particular situations in a manner that does not overlook or simplify the inherent complexity, uncertainty, or interrelatedness of the people involved in requiring, resourcing, and engaging in palliative care. Using Rolfe's and Jasper's[71] approach to reflection, the meta-understanding provides a means of engaging with 'what' in order to progress to the other questions 'so what' and 'what now'.

The importance of accounting for complexity and uncertainty is recognised in the literature. According to Charon[50] 'experience remains chaotic and formless until given form ... high-stakes, emotionally charged situations we experience around illness and death are particularly resistant to simply being undergone and understood on their own' (p. 8). Highlighting the importance of reflection, George and Lowe[72] propose that 'although uncertainty cannot always be reduced, our reactions to it can be altered with support and reflection' (p. 304) while Ferrell[67] proposes that to 'know what it means to care ... perhaps we need deeper reflection' (p. 305). Thus, we intend that the questions posed from our research provide scope for people resourcing, requiring, and engaging in palliative care to make sense of, and perhaps navigate and transform, approaches to palliative care that ensure humanity and caring are clearly in the foreground. For those resourcing palliative care services, a meta-understanding can be reminder to value what is difficult-to-quantify and consider what may be difficult to see. For those requiring and engaging in palliative care, a meta-understanding can focus reflections and conversations on complex and uncertain aspects of providing palliative care.

This research used a novel way of producing knowledge about important concepts related to palliative care. Collaborative inquiry enabled the exploration of these concepts to be undertaken with clinicians and researchers to ensure both clinical relevance and sound methodology. Appreciative inquiry, beyond being important as a lens to explore what works in palliative, facilitated involvement, and cohesion of the research group. Using philosophical hermeneutics to inform data interpretation enabled the findings to reach a conceptual level that embraced the data's inherent diversity. Attention to congruence, authenticity, and credibility of the research was important throughout the research. Congruence (in relation to the research topic and strategy) required a balance of making the theoretical underpinnings of the research explicit to all team members but not impeding research progress through the team getting 'bogged down' with research theory. Authenticity (of researchers interactions in relation to method) required a balance between meetings that were sufficiently regular to maintain research momentum and

Text Box 3. Questions to inform reflection and conversations about palliative care: making sense of, and navigating, particular situations.

While considering the meta-understanding of providing palliative care, we propose the following questions to reflect on and discuss in relation to (i) a '**tricky situation' with scope for 'doing it differently'** and/or (ii) a **'seamless' situation with scope for 'doing more like it'**:

- "What?"
  - Which parts of the meta-understanding stand out as particularly relevant to this specific situation?
  - What happened (or is happening) to make these parts stand out?
  - What were (or are) the implications for the people involved?
- "So what?"
  - How could it have been otherwise?
  - What insights can transform future practice?
  - What is required for this transformation?
- "What now?"
  - How might you contribute to this transformation?
  - What do you need from others?
  - How might this come about?

involvement of team members but were sensitive and responsiveness to team members' time commitments and ongoing availability. Credibility (in relation to research findings) required a balance between developing insights and meanings of the whole team through broad engagement with raw data and maintaining data interpretation momentum by KF's and AC's sharing insights and meaning that are supported by raw data. While not claiming to achieve a perfect balance of these at all times, deliberately seeking this balance enabled the development of our conceptual understanding to inform ongoing discussions and reflections.

While developed through single-site research, the conceptual nature of these attributes and actions potentially enables them to have applications elsewhere. Accordingly, we encourage readers to consider the relevance of our meta-understanding of providing palliative care to their own situations, including beyond Australia. We do this in accordance with the notion of transferability in qualitative research. There is scope for further research to explore value of the meta-understanding for transformation of practice in our setting and other settings. Importantly, there is also scope for patient's perspectives to challenge or enrich the conceptualisation.

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