Compassion is a core virtue in medicine and lies at the heart of good medical care. Its Latin derivation translates as, “with suffering”, thus compassion has a cognitive component; “it requires an imaginative indwelling into the condition of another, requiring identification with the victim” and suggests more than mere acts of basic care. In addition to cognitive and emotional perspective taking, compassion involves the additional step of wanting to alleviate suffering. It is “humble and powerful”, “felt” as an emotion, and requires a “complex subjectivity on the part of both the physician and patient”. Housset describes compassion “as the respectful awareness of being touched by the other person’s suffering”. Linked to sympathy and empathy, compassion connects us to each other and reflects our need for relationships with others.

Many professional codes of practice and standards of conduct are founded on the principles of trust, respect, dignity and compassion. Compassionate care improves health outcomes and patients’ care experiences. Bramley and Matiti explored patients’ experiences of compassion within nursing care and found that when nurses’ empathetic behaviour was felt by patients, the positive impact on overall wellbeing was clear. One patient spoke of her isolation in a side room and how speaking with a nurse about her isolation “just made me feel so much better”.

Conversely, a lack of compassionate care can exacerbate existential neglect and increase suffering as was evidenced in the Mid Staffordshire NHS Trust report that highlighted the “appalling suffering of many patients”. One of the recommendations of the report called for the Nursing and Midwifery Council to consider an aptitude test to be undertaken by aspirant nurses that would explore “attitudes towards caring, compassion and other necessary professional values”.

**ABSTRACT**

**BACKGROUND:** Compassion is a core virtue in medicine and lies at the heart of good medical care. It connects us to each other and reflects our need for relationships with others.

**AIM:** Our aim is to explore how palliative care patients perceive, understand and experience compassion from health professionals, and to inform clinical practice.

**METHODS:** Seven hospice managers in the North Island of New Zealand were contacted and invited to join the study. Twenty participants expressed a desire to participate and were involved in semi-structured face-to-face interviews. A set of questions guided the interviewers with interviews lasting between 15–60 minutes.

**RESULTS:** In regards to the question, what is your understanding of compassion?, four central themes emerged: connection, presence and warmth, respect and caring. When asked, what advice can you give to trainee health professionals?, participants articulated four themes: connecting with patients and talking in a way they can understand, treating the person with respect, showing interest in them and being a positive presence for them.

**CONCLUSIONS:** Compassion was seen as a connection between the carer and the patient. Compassion is having a positive presence and warmth; an attitude of respect and caring. The main advice given by research participants to enhance compassion is for doctors and nurses to connect, to talk in a way that can be understood, and show interest and respect to patients facing the end of their lives.
In discussing his diagnosis of malignant mesothelioma at age 57, Sweeney describes a sense of dislocation, lack of care, “one is left with the feeling that the professional does not care about me”, and isolation—“What I have always feared in illness was anonymity, being packaged, losing control, not being able to say ‘this is who I am’. In the end, one is left alone, here, in the kingdom of the sick.”

Compassionate care at the end of life is central to dying well. It encompasses listening and spending time with the patient, empathetic rapport and bedside manner, listening and respecting patients, and helping patients manage the hospital environment. A number of studies have explored patients’ perceptions of their care, care from the perspective of health professionals and compassion fatigue among health professionals. As far as we are aware, no studies have addressed the concept of compassion solely from the perspective of palliative care patients. All patients deserve compassionate care but more so at the end of life when patients are vulnerable, often isolated, suffering emotionally and physically and are facing imminent death. Such patients offer important insights, which may assist in optimising their quality of life until death by addressing their physical, psychosocial, spiritual and cultural needs.

The aim of our study was to explore how palliative care patients perceive, understand and experience compassion from health professionals, and to inform clinical practice.

Method
Setting/participants
Seven hospice managers in the North Island of New Zealand were contacted and invited to join the study. The research team discussed with the hospices the plans and aim of the study, the rationale for the research and the requirements of the hospice involved. While four hospices agreed to participate in the study, most participants came from the first hospice that signed up for the study. Nurse coordinators contacted eligible participants who were advanced palliative care patients, gave them a copy of the participant information sheet and the consent form and then emailed the researchers with the willing participants’ name, contact number(s) and diagnosis. Twenty-seven agreed to be initially contacted by the research team by phone while 21 individuals indicated their desire to be involved; one person refused when she realised she knew of one of the researchers so she was excluded in the final list of participants. Ethical approval was sought and gained by the University of Auckland Human Participants Ethics Committee (UAHPEC) for three years (Reference number 013082). As per committee requirements, all participant information collected was anonymised, and transcribed interviews stored securely on password-protected computers. Involvement in the study was voluntary and individuals gave their written consent before interviews commenced. Participants were advised that they could stop the recording device at any time. The digital recordings and transcripts will be securely kept for a period of six years as per UAHPEC requirements. Recruitment of participants took place from November 2014 and January 2015.

The study population consisted of four males and 16 females with a mean age of 61.35 years. Fifteen participants identified as Pakeha/European descent, three identified as Asian, one as Māori/European and one participant was from the Pacific Islands. In terms of diagnoses, 18 participants had advanced, metastatic cancer, and two had end stage emphysema/COPD.

Eighteen interviews were conducted in the participants’ own homes. One was interviewed in the hospice and another participant in an interview room at the University of Auckland. As per their preference, most participants were interviewed alone while five had a family member with them during the interview. Participants were given a $20 voucher as token of appreciation.

Data collection
Semi-structured face-to-face interviews were undertaken. AF and CR conducted the interview process. No relationship was established with participants prior to study commencement. A set of questions guided the interviewers (See Table 1), however the style of the interview was conversational, allowing deviations from the key questions to capture a richer perspective of compassion from participants. Participants were interviewed once lasting between 15–60 minutes with the interviews averaging around 30 minutes. Each interview was digitally recorded on two recording devices.
Data analysis

Thematic analysis was employed as a research tool because it gives a rich and detailed account of complex data. Such an approach allows for the identification of central thematic categories from interview data related to participants’ understandings of compassion, their experiences of compassionate care and experiences of a lack of compassion. Analysis of the dataset was undertaken by AF, CR and PJM. The researchers independently immersed themselves in the verbatim interview transcripts, noting down how prevalent themes were articulated by participants as well as repeated patterns which resulted in potential coding themes. During subsequent meetings these were discussed and debated until final themes were confirmed. This ensured a rigorous and consistent method of analysis. The research team followed the COREQ protocol for reporting of qualitative data.

Results

What is your understanding of compassion?

Four central themes emerged from analysis of the interview transcripts: connection, presence and warmth, respect and caring. A number of sub-themes emerged throughout the refinement process and provided structure and support to the themes identified. Although we distinguish the four themes as separate groupings for ease of comprehension, they are intimately woven together and in fact cannot be seen as wholly separate from each other.

Table 1: Interview schedule.

<table>
<thead>
<tr>
<th>Question</th>
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<tbody>
<tr>
<td>What is your understanding of compassion?</td>
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<tr>
<td>Have you experienced a health professional who was compassionate?</td>
</tr>
<tr>
<td>• Can you tell me about that experience?</td>
</tr>
<tr>
<td>• In what way did that person show compassion?</td>
</tr>
<tr>
<td>Have you experienced a health professional who showed a lack of compassion?</td>
</tr>
<tr>
<td>• Can you tell me about that experience?</td>
</tr>
<tr>
<td>Do you have any advice to doctors or nurses about compassion?</td>
</tr>
<tr>
<td>Why is compassion important to you as a patient?</td>
</tr>
</tbody>
</table>

Connection

Within the theme of connection, several subthemes emerged, including understanding, empathy and sympathy. The connection between participants and doctors and nurses was often exemplified by their strong relationships and the depth of sharing they experienced. The connection was seen as an intellectual (‘I understand’) and emotional (‘I feel’) state. It bound the patient and health professional together. This was powerfully illuminated by the participant who spoke about the registrar she had never met who, when she walked into the room said;

“I’ve just been reading your notes, you’ve had a terrible year. And you know to me I just thought, oh you, I could feel that connection, like she had really read the notes and understood it”. (Female, 58 years, European)

Being able to identify with the participant by understanding their situation and connecting with them through physical touch were articulated as part of what it is to be compassionate;

“...it’s somebody who can empathise, try and put themselves in another person’s shoes. From the point of view of trying to care for that person...”. (Female, 75 years, European)

“...the big difference is those who touch you, strange as it sounds, they just don’t have to say anything. Come in and put the hand on your back, rub your arm, sometimes hold your hand and say ‘how are you feeling today’ and things?”(Male, 73 years, European)

Presence and warmth

The subthemes providing structure to this theme included, being positive, uplifting, warm-heartedness and friendliness.
For many participants, compassion was a felt presence of a professional who was pleased to see them, was sincere and was there for them. Sometimes compassion was as simple as a smile or sharing a joke.

“...he is always happy to see you... he never acts as if there is anything else he needs to do, except see you”. (Female, 48 years, European)

“...he is warm, his aura is really lovely you know. He greets you with a smile every time and he will chuckle away with you”. (Female, 47 years, European)

Respect
A number of subthemes were identified and included, being heard and being listened to, professionalism, non-judgemental, being valued as a full person, honesty and openness, eye contact and dignity.

Being attentive to the varied challenges arising for participants as they faced the enormity of their situation was central to their understanding of compassion. Several participants spoke of the importance of being treated as intelligent individuals and not merely as a medical condition or a number.

“I am respected for who I am not because I have got cancer or because I am undergoing chemotherapy. I’m just respected for being”. (Female, 46 years, European)

“It’s people being honest with you. Not treating you as if you are an idiot. It’s people that treat me with respect, people who give me information. People who give me time to ask questions”. (Female, 46 years, European)

For others, compassion was demonstrated by being fully present in the encounter and being on time.

“He is very, very caring, and he is never late for his appointments...because you know the worst thing you can do is go to the doctors and sit down and wait for three quarters of an hour”. (Female, 69 years, European)

Caring
Caring was a complex theme that incorporated a number of subthemes, including encouragement, reassurance, support, comfort, love, being the focus of care, commitment, responsiveness and sensitivity in relieving suffering.

When participants were asked their understanding of compassion, many spoke of it as entailing care. Care reflected attention and sensitivity to the moment.

It was about comfort and encouragement when life was difficult and circumstances required support. Participants often gave examples of care that involved kindness;

“We just chat about things and they put their arm around me when I am crying”. (Female, 69 years, European)

and sensitivity in the relief of suffering;

“I got cramp in my legs and he went down on his knees on the floor in his surgical gumboots, massaging my calves to make me comfortable”. (Female, 55 years, European)

Have you experienced a health professional who was compassionate?

When asked this question, many participants immediately gave an example of what compassionate entailed.

“I was dealing with this stoma and they were teaching me whilst I was in hospital how to manage it. And sometimes I would have blowouts like you wouldn’t believe. And I was virtually lying in it. And these lovely nurses that were there, they had to clean me up. I thought if those people can do that for me I will never complain again, so that really touched me”. (Male, 73 years, Māori)

A compassionate nurse who exemplified the qualities of kindness and thoughtfulness, and whose action was supererogatory in nature was articulated by one woman who said:

“Oh there was yes one nurse. Because when I got admitted I didn’t have any hair, and it was winter time. And it was cold. And I asked them if they had any head gear because I had just gone in. And there was nothing on the ward but one of the nurses went down to her car and she had a knitted cap which she brought up to me, and that to me that was really compassionate”. (Female, 75 years, European)

Have you experienced a health professional who showed a lack of compassion?

Participants recalled situations when they felt rushed, devalued, dismissed and misunderstood by health professionals. Struggling to understand what was being said and feeling that one wasn’t being listened to also typified some experiences where a lack of compassion was revealed by participants. One man recounted the conversation he had with the oncologist who;
“...tells me I’m going to, my hair’s going to fall out and this is going to happen. Chemo's going to work for a while and then you're going to be dropping dead in December. I said ‘thank you very much mate’”. (Male, 60 years, European)

Another participant recounts the situation of a man in his ward who was having difficulty breathing;

“And I could tell what he was going through and the nurses they knew he was going to die. But she didn’t touch him. She just sat there, she might as well have been knitting, watching him die. And I got really angry”. (Male, 73 years, European)

Both compellingly communicate their sense of frustration and anger at the lack of compassion.

What advice can you give to trainee health professionals?

Four themes emerged from the data and underpin the importance of connecting with patients and talking in a way they can understand, treating the person with respect, showing interest in them and being a positive presence for them. These were central to the advice given to trainee health professionals.

“Just try not to be judgemental because you really don’t know what has gone on in that person's life and how they have gotten to this point”. (Female, 60 years, European)

“Don’t be too quick, take time to communicate with the patient”. (Female, 70 years, Asian)

They need to “look after their own well-being so that they don’t become needy themselves”. (Female, 48 years, European)

Why is compassion important?

By far the most significant answer given in response to this question was that health professionals recognise the vulnerability of patients near the end of life. Participants spoke of needing guidance and help along the dying trajectory and what to expect as death approached. Feeling safe, relaxed and comfortable, as well as being encouraged were also articulated by participants.

“...you are just a number that’s how you feel and you feel just a number. And you are not a number. You are a person and you have got feelings and you know you have got this terrible illness that you know you are not going to live through it”. (Female, 69 years, European)

“...When you have cancer, especially in a metastatic situation you need to feel loved and cared for. You need that. You need to know that somebody really does give a damn”. (Female, 47 years, European)

“(compassion) it is a free service...and it can make such a difference if you...but it’s got nothing to do with a medical outcome but often it’s what you remember”. (Female, 48 years, European)

Discussion

Compassion is an expectation in the medical care of all patients. Specifically palliative care patients, who are especially vulnerable as they face imminent death, need genuine compassionate care. Though there is a need to explore palliative care patients’ perspectives of compassionate care, there are no studies to date that inquired of these patients’ voices regarding compassion. This study addresses this gap in knowledge by exploring how palliative care patients understood and experienced compassion from health professionals. They also shared their insights as to how doctors and nurses can become more compassionate.

In this study, several themes of compassionate care emerged. Compassion was seen as a connection between the carer and the patient. Compassion is having a positive presence and warmth; an attitude of respect and caring. All the participants in this study witnessed and experienced compassionate care towards them from doctors and nurses. Most have also seen or experienced health professionals who showed lack of compassion where they felt devalued, not listened to or just plainly ignored. The main advice given by research participants to enhance compassion is for doctors and nurses to connect, to talk in a way that can be understood and show interest and respect to patients facing the end of their lives.

Our findings are very similar to results reported from previous research on hospital patients and a mixed sample of older patients with chronic diseases. The themes of caring, being treated as a person instead of a checklist, and clinicians making time or being available to patients were also mirrored in previous studies. A further study mentioned the experience of positive presence and warmth by the clinician.
positive presence is a patient’s perception that the clinician chooses to be there, and to consciously and quietly be with the patient. Compared to other descriptors of compassion, presence and warmth are harder to operationalise and appear less concrete, but patients cherish and emphasise these experiences.

As expected in this study, examples of lack of compassion from clinicians and nurses are the antithesis of participants’ experiences of compassion. Participants talked about not being valued, not being listened to or simply being ignored. Similarly, a previous study noted staff making elderly patients wait to use the toilet because of staff shortages as an example of lack of compassion. The issue of not giving time in the current healthcare climate is complicated because of competing pressures to see more patients while spending more time performing administrative work and documentation. However, while participants in a previous study understood that staff are pressured timewise, patients said that a compassionate act can be fleeting and not necessarily time consuming.

In the Transactional Model of Compassion, compassion and barriers to compassion are seen as emergent from dynamic but interrelated influences of clinician, patient and system factors. In this and previous studies, patients focused only on the clinician: those clinicians who were seen as dismissive, not listening, uncaring and not involved. Patients in this study did not mention other factors that may contribute to a lack of compassion, including system issues (eg, a chaotic ward environment or a busy ICU) and difficult patients and families. Systemic factors, particularly the busy nature of the clinical job, were identified in a previous study as an issue that prevents clinicians from giving time.

In relation to the current two-fold definition of compassionate care, that is, empathy or perspective taking with subsequent relief of suffering, patients in this study viewed compassion in a broader sense. They talked about compassion as involving a particular quality of relationship which is warm with a positive presence and respect, which may not necessarily be part of pain or symptom relief. They also talked about an interaction which involved connection and care. Compassion “can be as quick and as easy as a gentle look or a reassuring touch”. With this in mind, a more nuanced description of medical compassion is an emotional and/or cognitive perspective, with a motivation to relieve suffering in a caring manner.

**Conclusion**

This is the first study we are aware of that explored how palliative care patients perceive, understand and experience compassion from health professionals, and how these understandings may inform clinical practice. It is well known that in most industrialised countries, the population is rapidly aging, highlighting the importance and significance of end of life services. Though compassion is central to dying well, practicing compassion is “free” and cost neutral, will benefit patients at the end of life, as well as their families and potentially the clinicians themselves.

In terms of limitations, the study is not generalisable to the palliative care population because we only focused on a small sector of patients who were under hospice services. Despite the study being open to all palliative care patients within the hospices approached, the average age of participants was 61 years, thus we did not hear from younger patients who may have had different perspectives on compassion and compassionate care. Even though several hospices within the greater metropolitan Auckland area were approached, most patients came from one hospice where the nurse coordinator was very organised and efficient in recruitment. The sample was not ethnically diverse, with the majority of participants identifying as New Zealand European. As our study was undertaken in urban areas it did not encompass patients in some rural areas that may not have access to hospice services. We suggest further research incorporating these factors be undertaken.

Strengths of the study include its focus on a specific, very vulnerable patient population whose voice on compassion has not been heard. The data was rich and clear themes emerged, which were consistent with previous studies. The findings add to our knowledge of what is important to patients facing the end of their lives within the context of compassion and compassionate care.
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