

Ever decreasing circles: terminal illness, empowerment and decision-making

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ABSTRACT

INTRODUCTION: Empowerment is the personal and political processes patients go through to enhance and restore their sense of dignity and self-worth. However, there is much rhetoric surrounding nurses facilitating patients' daily choices and enabling empowerment. Furthermore, there is frequently an imbalance of power sharing, with the patient often obliged to do what the health professional wants them to do.

METHOD: This phenomenological study describes the lived experience of patients attending an outpatient clinic of a community hospice. A qualitative study using Max van Manen's phenomenological hermeneutic method was conducted to explore issues surrounding empowerment and daily decision-making with terminally ill patients. The participants' stories became a stimulus for learning about the complexities of autonomy and empowerment. It also engendered reflection and analysis of issues related to power and control inequities in current nursing practices.

FINDINGS: The results revealed not only the themes of chaoticum, contracting worlds and capitulation, but that health professionals should be mindful of the level of control they exert. Within the palliative care setting they need to become partners in care, enhancing another person's potential for autonomous choice.

CONCLUSION: Empowerment must not be something that simply occurs from within, nor can it be done by another. Intentional efforts by health professionals must enable terminally ill people to be able to stay enlivened and connected with a modicum of autonomy and empowerment over daily decisions, no matter how mundane or monumental they might be.

KEYWORDS: Phenomenology; empowerment; autonomy; terminal care; decision-making

Introduction

There has been little research conducted exploring terminally ill patients' self-empowerment and decision-making within their day-to-day lives.¹ Anecdotally terminally ill people tend to be treated as a homogenous group, as though they all suffer and behave in the same manner.^{2,3} The end result is that the therapeutic relationship becomes a 'one size fits all' model,^{1,4,5} which can leave the person and their family members feeling disenfranchised, frustrated and not listened to.¹ A terminally ill person's day-to-day decisions may seem to others mundane and redundant, but being allowed to make them can often enable a person to continue to feel empowered, autonomous and self-willed.⁶

Decision-making by terminally ill adults has been described as a performance concerning autonomy that involves a variety of players.^{7,8} The right to be autonomous and make decisions about their own lives is a commonly accepted ethical principle.⁷ However, pragmatic nursing styles that encourage 'doing for' rather than maintaining a presence with a terminally ill person, tend to disable many autonomous decision-making abilities and processes.⁸

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erment.^{10,5} Historically nurses have been taught about the importance of autonomy in patients,¹¹ yet it is debatable whether consideration of empowerment is truly incorporated into practice. While the idea of empowerment is naturally appealing, its application becomes weakened because of its abstract ambiguity.^{6,4,12,13} Furthermore, there is frequently an imbalance in power sharing, with the patient feeling obliged to be humble, in the process left feeling humiliated and inconsequential.^{14,15}

This paper reports the findings of a qualitative study with the aim of exploring issues of empowerment and daily decision-making from the perspectives of people who are terminally ill.

Method

It was decided that qualitative methods, using a hermeneutic approach,¹⁵ was the best way to achieve the aims of this study. Such an approach examines and reveals the language buried within the meanings of words. The participants' stories allowed glimpses into the lived experience of the world of people diagnosed with terminal illness. Reflections of the 'self' were revealed along with the subjective nature of integrity, spirituality and wholeness, thereby enabling the activity of phenomenological thinking.¹⁵

Phenomenology is described as 'being in the moment', of living the experience with someone else and discovering something worthy of recording.¹⁵ Phenomenology is a style of thinking, as well as a philosophy, and the intention is to describe or understand a moment in someone's life by interpreting recollections. The most natural way of doing this is to narrate from lived experience.¹⁵ By being part of the narration process, the researcher refrains from judging and concluding what is right or wrong, but rather participates in the story. Phenomenology thus systematically attempts to uncover, describe and discover the nature or essence of the experience; in this case, of living with a terminal disease.¹⁵

Fourteen participants receiving palliative care were selected and recruited by a doctor at a community hospice and invited to participate in an individual interview between May and June 2005. Five males and six females agreed to participate in

WHAT GAP THIS FILLS

What we already know: Decision-making for people nearing the end of life is difficult for a number of reasons. Despite improvements in communication and management near the end of life, patients and their families often feel disempowered, vulnerable and frustrated.

What this study adds: Primary health professionals need to work actively towards ways of empowering people who are dying by paying attention as much to the *being* aspects of care as to the *doing* aspects. Self-reflection and positive regard within the therapeutic relationship can enhance the experience for those who are dying.

the study. Ten were Anglo-European and one was of Polynesian descent. The age range was from 48 to 84 years. Cancer was the primary diagnosis for 10 participants, with one having heart disease. All the participants came from one small geographical area of New Zealand. Face-to-face interviews were audiotaped (once consent was gained) and later transcribed verbatim by the researcher. All of the participants had died by the time the study was written up. Pseudonyms have been used to protect the identity of the participants.

The steps that guide a study undertaken using Van Manen's approach are summarised in Table 1. Transcribing of the interviews by the researcher enables immersion in the transcripts in order to understand abstraction and develop themes that reveal phenomena through the narratives of lived experience.

A commitment was made to stay close to and intimate with the original data and this was achieved through total immersion in the text—reading, listening, re-reading and reliving the memories of the interview with each of the participants. Careful line-by-line analysis revealed common themes.¹⁵

Ethical approval was gained from the University of Otago Board of Graduate Studies, Community Hospice Ethics Committee, Lower South Regional Ethics Committee, Ngai Tahu and a member of the Chinese community.

Findings

Three key themes were identified from the data. The first relates to participants' *lived space* and was called 'chaoticum', as the participants lived within a chaotic and complex time in their lives.¹⁵

The participants reported that their lives spiralled out of control after being given their diagnosis. The second theme relates to the *lived body*¹⁵ and this was called ‘contracting worlds’; participants spoke of forfeiting normality as their worlds began shrinking around them in ever decreasing circles. The final theme relates to *lived time*¹⁵ and was called ‘capitulation’ because the experiences revealed a time when the participants became submissive and acknowledged that their lives were coming to an end.

Chaoticum

The lived experience of the participants revealed a world that was, for them, a mixture of chaotic time and chaos. Their worlds were freewheeling out of control, leaving little time to deal with things. Participants experienced disharmony, anger, disbelief, chaos and powerlessness, as this extract from the interview with Jane reveals:

I’ve been given my life sentence; I know I’m going to die but it is the unknown. Am I going to get sick, what’s going to happen to me?”

Sage talks about her total disbelief and anger at the doctor being honest about dying, thus capturing the conflicting emotions and needs at this time in her life:

I was angry, I was bloody angry with the doctor when he told me I was going to die... I didn’t know where to start with things. There seemed so little time to fix things you know.

Furthermore, Jessica talks of living in a house that was very chaotic:

It was a sick house. I would just lie on the floor... it was depressing because I couldn’t do anything about my life. We lived in a very sick messy chaotic house all of the time.

Another participant, Bruce, appeared upset at the chaos that he had left for someone else to sort for him:

There is stuff at the house that someone else will have to sort because I don’t have the energy. They will have to sort out the mess because for two months I haven’t had the energy to fix my life...

Contracting worlds

Participants described the way they had to give up things in their lives; the forfeitures, losses, decreasing circles and disempowerment that they experienced. Not only were their social lives contracting, but physically they were also suffering from contractures as their bodies started to change and shrink from their former self. This is captured by Virginia who felt very vulnerable and disempowered when she made trips to the clinician:

I felt terribly disempowered in the hospital setting by the oncology doctors. Just going for a check up and I would come out and think God how am I supposed to keep my hopes up when there was such a grim sort of background, a feeling of abandonment and just the odd comments. I felt so very disempowered... Apart from hope. I don’t want them to take that away from me you know.

Connie described how she maintained some semblance of normality as she tried to retain a belief that her world was not changing, by washing herself and undertaking other personal care:

I don’t want others doing my personal stuff for me because that would mean that I was no longer a person...

This is further reflected by Grace who commented:

I got quite bitter for a while. This disease can let your bodily functions go a bit in front of people and I was disgusted.

Table 1. Van Manen’s Phenomenology (Adapted from van Manen, 2002²³)

Two aspects of methodology	
1. The reduction:	Bracketing or suspension of everyday ‘natural attitude’
2. The vocation:	Letting things ‘speak’ or be ‘heard’ through text
Six empirical methods	
1.	Describing experiences
2.	Gathering experiences
3.	Interviewing experiences
4.	Observing experiences
5.	Fictional experiences
6.	Imaginal experiences

Clearly, these participants resented the way their bodies were failing and wanted to continue to care for themselves for as long as possible.

Capitulation

The third theme captures the participants' understanding that they were only temporally in the world. Participants found that the closer to death they got, the more submissive they became until they finally began to make those final end of life arrangements as reflected in Virginia's words:

There are days that I feel like I have gone back several more steps and I have to rely a lot on others now because I don't know when my body will give out. I feel like I have to wait on other people to do my 'stuff' and I feel quite powerless.

Bruce grieves for the loss of his past life as he gave in to his inability to manage for himself:

Two months ago I was still working and now look at me I am little more than a baby.

Harry was also feeling a sense of giving-up when he commented:

I hated hospital. They (nurses) woke me up every two hours shining a torch in my eyes. I couldn't sleep all week and I am not sure why because I wasn't dying. I hated it and I am never going back because I couldn't do what I usually do. You are just stuck there whether you like it or not.

Whilst Jane describes accepting her terminality:

I've just dealt with the thought of dying. Tomorrow the funeral director lady is coming. I know I have got to get some things in order.

Discussion

Individuals make decisions based on personal strategies and judgments, influenced by biases and rules, especially when there is an unknown future ahead.⁶ Decision-making, therefore, is a complex and multifaceted phenomenon. It is difficult to deconstruct an individual person's thoughts, feelings and behaviours and match them to the different facets of decision-

making.² This study has allowed the words of a small number of people living with a terminal illness the chance to describe their lived experience at a particularly challenging time in their lives. Each of these experiences, and the subsequent themes that emerged, emphasise the need for empowerment, especially during the last period of life, since individuals are more likely to make decisions based on the availability of information, on instances or recent occurrences.¹⁵

Recent research indicates that terminally ill people consistently perceive that they have a less active role in their daily decisions than they desire.⁵ Others start making valued judgements for them, especially health professionals, because they are considered to be too vulnerable, less of a person, thought to have lost the ability to think or too sick to make choices. Terminally ill adults can make decisions and do so based on a broad range of factors, such as spirituality, values and beliefs, that subsequently influence how they respond to everyday challenges.¹

There has been much criticism concerning ethical decision-making over recent years¹⁶ as bioethical discourse has focussed on the ideal, rather than what actually happens. Many ethicists believe that only rational or logical decisions are the right ones, but attention should also be paid to 'what genuinely moves people to act, their motivations and passions, loves and hates, hopes and fears.'¹⁶ In this study, this is supported by Connie's experiences when she commented:

I didn't want people deciding for me right up until I can no longer talk.

Hunsaker Hawkins¹⁶ suggests that small clinical aphorism and literary narratives can be a powerful vehicle for moral reasoning and transporting you deep into another person's world for a brief time. Phenomenology allows both the narrator and the reader to be transported into the narrator's world.¹⁵

This research reminds nurses of the importance of reflecting fully on how they can help meet the wishes of a person who is terminally ill. There is

a need to ask and keep asking whilst also being prepared to listen.

Each of the participants in this study wanted someone who was not constantly doing but rather listening or simply being there. This is aptly captured by Harry when he describes how he insisted that he keep to his daily schedule because without that he knew that he would just curl up and die:

I didn't want the nurses coming to my house and doing my washing or chores and I had to keep telling them this. If I want to walk half way across town with bags of laundry when the weather is wet then that's what I want to do. They kept trying to make me do things on their timetable but I had other ideas.

When people are given a terminal diagnosis there is a point in the care continuum when these people feel abandoned by the biomedical model along with feeling a sense of not belonging.¹⁷ Such people are different to many of our other patients because there are no happy endings, no cures or achievable health outcomes except for the desire and hope for a perceived good death. This study revealed that terminally ill patients want nurses to become a fully-engaged being when entering the therapeutic relationship, whilst at the same time to recognise that people who are dying are unique and unpredictable in terms of the connection and dependency within the nursing/patient relationship.¹⁷

Empowerment is central to decision-making and people who are seeking health care need to be enabled and empowered to make their own informed choices.¹⁸ Health professionals can never fully understand what the patient is going through, but they can ease the path by their own critical self-reflection, listening, intuitive caring and thought.¹⁹ Illness and disease make people deviate from their chosen life path and typically the clinical world has its own customs and culture that can be difficult to understand. Throughout the terminal illness journey nurses should endeavour to enable people to remain informed and self-empowered.¹⁷ Moral autonomy, according to Kant, is a combination of freedom

and responsibility; a truly autonomous person cannot be subjected to the will of another.⁶

The findings from this study suggest that health professionals need to think more about power and control issues and explore how they can become partners in enhancing another person's potential and autonomous choices.^{6,8,10} Empowerment describes the intentional efforts to create a more equitable relationship and a living within someone else's world.¹⁹ How a patient exercises their empowerment and control depends on individual engagement, ability and 'the adoption of a person-valuing approach'.³

For any moral engagement to work within a particular given time and space there has to be a comfortable social and emotional congruence driven by integrity and honesty.^{1,20} Health professionals must not be afraid to enter territory that is uncomfortable or unknown. There needs to be open, unconditional positive regard shown towards every patient for whom we care. Finally, there must be empathic understanding or 'sensitive active listening' not only to the person, but careful listening to what stories their body can tell us.²¹

This is summed up by Connie:

I felt embarrassed and I found it very difficult I didn't want other people touching me but when I got sicker you have to get over that and you can't do it for your self so you have to let others do it for you. But I still don't want other people making choices like what I am going to eat. I don't want others picking out my food for tea for me.

Limitations of this study

The most significant and limiting factor was that most of the participants died before their transcripts could be transcribed and reviewed. This is a reality in all research where participants have terminal illness. However their stories are important and it is the engagement of the researcher with the participant that enables the revelation of the essence of something. Phenomenology does not offer the possibility of theory that looks at variables or controls. It does, however, offer the plausible insights that bring us into contact with people's lived experience, in and around us.

Research implications and recommendations

These findings highlight the need to critically reflect on practice in a rigorous manner on a daily basis. They should serve to enlighten health professionals' internal and external practices and encourage engagement in self-analysis as truly caring beings.²² It is necessary that health professionals actively consider the concept and importance of empowerment. However, more research needs to be undertaken to understand strategies related to how empowerment works and the notion that 'empowerment is undermined by the seduction of health-discourse so that the patient ends up wanting what the system wants them to want' and who it works for.¹⁰ Further study is also needed on the effectiveness of *being* instead of *doing* for our patients.

Conclusion

'Phenomenology, like poetry, intends to be silent as it speaks. It wants to be implicit as it explicates.'¹⁵ When we enter the world of the patient and actively listen to them, we become accustomed to their manner of speaking, what is important to them and what individuates them at this particular point in time. Listening enables us to get underneath the surface of the individual and their experiences. By using van Manen's approach to researching lived experiences, this study reinforces the importance of empowering those who are terminally ill to remain in control of their day-to-day decisions for as long as possible. The themes reflect key issues that nurses should reflect on and learn from, so that, when caring for and working with the terminally ill patient, this fully engaged being requires different nursing skills because of the unique and unpredictable psychosocial terms of reference that nurses have to work within.

For each of the participants, it was everyday decisions that concerned them greatly, not the big, life-changing ones. All of the participants wanted their experiences with a terminal illness to be their own and to be allowed to die in their personal way, thus enabling autonomy and rationality. A positive regard needs to be revealed before any therapeutic relationship can ensue. People who are terminally ill are unique

and unpredictable in terms of the connection and dependency within any nursing relationship; therefore it is imperative that, between the carer and the cared for, empathic, intuitive, active listening occurs, resulting in empowerment, feelings of being valued and respected, and enabling the best possible death.

References

- Gauthier DM. The contextual nature of decision-making in a home hospice setting. [Dissertation]. [Galveston]: University of Texas; 2001.
- Gilbert T. Nursing: empowerment and the problem of power. *J Adv Nurs*. 1995;21:865–71.
- Powers P. Empowerment as treatment and role of health professionals. *Amer Nurs Standard*. 2003;26(3):227–238.
- Paterson B. Myth of empowerment in chronic illness. *J Adv Nurs*. 2001;34(5):576–81.
- Gauthier DM, Swigart VA. The contextual nature of decision-making near the end of life: hospice patients' perspective. *Amer J Hos Pal Care*. 2003;20(2):121–8.
- Kant I. The critique of practical reason. Trans. Lewis White Beck. New York: Macmillan; 1788, 1985.
- Sahlberg-Blom E, Ternstedt M, Johanson J. Patient participation in decision-making at the end of life as seen by a close relative. *Nurs Ethics*. 2000;7:296–313.
- Beauchamp, TL, Childress, JF. Principles of biomedical ethics. 4th ed. Oxford: Oxford University Press; 1994.
- McLean A. Empowerment and the psychiatric consumer/ex-patient movement in the United States: contradictions, crisis and change. *Soc Sci Med*. 1995;40(8):1053–1071.
- Richardson K. Ever decreasing circles: non-curative terminal illness, empowerment and decision-making: lessons for nursing practice. A thesis submitted for the degree of Master of Health Science at the University of Otago, Dunedin, New Zealand; 2005.
- Benner P, Wrubel J. The primary of caring: stress and coping in health and illness. Menlo Park: Addison-Wesley; 1989.
- Opie A. 'Nobody's asked me for my view': users' empowerment by multidisciplinary health teams. *Qual Health Res*. 1998;8(2):188–206.
- Keiffer CH. Citizen empowerment: a developmental perspective. *Prev Human Serv*. 1984;3:201–26.
- Freire P. Pedagogy of the oppressed. London: Penguin Books; 1970, 1972.
- Van Manen M. Researching the lived experience: human science of an action sensitive pedagogy. London: State University of New York Press; 1990. p 131.
- Hunsaker-Hawkins A. Stories and their limits: narrative approach to bioethics. Lindemann-Nelson H, editor. New York: Routledge; 1997.
- Dworkin G. The theory and practice of autonomy. Cambridge: Cambridge University Press; 1988.
- MacLeod RD. On reflection: Doctors learning to care for people who are dying. *Soc Sci Med*. 2001;52:1717–19.
- Cumbi SA. The integration of mind-body-soul and the practice of humanistic nursing. *Holi Nurs Practice*. 2001;15(3):56–62.
- Benner P. From novice to expert. California: Addison-Wesley; 1984.
- Polkinghorne D. Narrative knowing and the human science. Albany: State University of New York Press; 1988.
- Montello M. Narrative competence. Stories and their limits: narrative approaches to bioethics. Lindemann-Nelson H, editor. New York: Routledge; 1997.
- Van Manen M. <http://www.phenomenologyonline.com/inquiry/1.html> 2002

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COMPETING INTERESTS

None declared.