
A paper given by Elizabeth Niven

Good afternoon. Thank you for coming to this session.

I am a doctoral student in the Department of Nursing and Midwifery at the Albany Campus of Massey University. My study looks at the individual and composite experience of those sharing a dying. I am interviewing the dying person (the Patient), the person most close to the patient at this time of his life (the Son) and the palliative care nurse providing and facilitating care for them.

One of my participants, whom I shall call Ivan, was a gentleman of Eastern European origin in his mid sixties. He had cancer, relatively advanced at diagnosis, with a prognosis of two to three months. His son, whom I shall call Michael, did not live with Ivan, but was in frequent contact, and provided support. The palliative care nurse, whom I shall call Mary, had a practice in a large hospital which both provided some direct care and a consultation service for the hospital and community. Care was provided by many others, but I interviewed only these people.

Ivan had a life of variety, drama and danger before coming to New Zealand, and these experiences remained influential to the end. During one of my visits Ivan told me that he wrote poetry. I was particularly taken with one: Invitation to the Last Waltz. I asked Ivan if I could edit it and use it in my thesis. He agreed.

In his poem, Ivan describes a dance with his old adversary. Ivan is partnered with the jesting Death, but slips away. The dance moves on, and Death partners with others in Ivan's life, leading them into the final moves. All the time, Ivan knows he will ultimately be claimed by Death. Yet, life still stirs him, he has love and life left. But, no one is there for him, and his heart fills up with pain. Death offers solace. Eventually, he puts aside his regrets and his unrealistic dreams and welcomes Death's embrace.

Ivan is a man who has danced closer to the shadows of death than most of us. He has been under fire in war, involved in hand-to-hand combat when he stabbed to death the soldier who raped his mother; he has been sentenced to death by firing squad, sent to the prison camps of the USSR and survived a mine collapse. I asked him how these previous brushes with death compared with the current situation. He said that it was different:

"because it was a condemnation of, ah, a human nature. There was a court of appeal. You know. So where there was life, you appealed, and you fought, and you appealed. But in this court, it is the highest. I cannot appeal"
(Ivan, 2, p3)

The issue I have chosen to explore is that of control -- who is in charge, autonomy, whose life is it. The phenomenon I will use is Ivan's reluctance to begin morphine.

When I first met Ivan, he had not commenced taking morphine for pain, though it had been prescribed and recommended. During this first visit the microphone jack became disconnected slightly, and recording halted. I made notes on the missed conversation.

"I need also to talk to him some more - or rather, have him talk to me - of his pain. He does not wish to take morphine. His pain reminds him that he is alive, and he is still in control. Morphine would be giving in - not just to the idea of dying, but it would be acknowledging the significance of the disease and his inability to be in charge. There seems to be some complex issues there, which I caught a glimpse of".
The next week I visited again and I brought up the subject. By this time, he had commenced on MST, long acting morphine, and he commented that it was now more difficult to remember the pain. I asked him about the significance of the pain. I said:

**EN:** . . . Ah, you were really reluctant to be without the pain, that is what I was hearing.

And he responded:

Ivan: no, I wasn't reluctant to live without the pain, I was reluctant to be without senses or feelings. So, it might be uncomfortable when a baby (in utero) kicks, but you don't want to be without it, because then you wouldn't know whether the baby is alive or dead.

**EN:** I had the impression that the pain's meaning was more than physical to you. . . .

Ivan: sure. . . Especially for my family. I must be honest, I can't camouflage it, and make people believe that everything is hunky dory. If I am not aware what is going on with me, I mislead myself and I mislead other people as well.

. . . it might sound a bit cruel to say, well, I want my family to know – that not everything is hunky dory. And the only way I can tell them, is if I am aware of my own physical presence. Not when I am doped up to my eyebrow and I am seeing hallucinations.

I asked him how it was, now he had begun the MST.

Ivan: it is an experience, ah, Elizabeth. On its own. Though I like drinking, I don't think I was more than twice in my life a few times drunk. Ah, I like to keep control of my faculties. And, that's probably overcome my fear of pain, fear of death. Make no mistake, I might put up a brave face, but underneath I am just as scared as anybody else. Of the unknown. But I prefer to be aware of it, than to be ignorant of it.

I asked Mary, the palliative care nurse, about the morphine situation. Mary had talked of Ivan's wife's illness and death from cancer some ten or more years earlier. She felt he was influenced by these memories.

Mary: “. . . when I first went to him, that very first time, he was actually charted, and meant to be having MST and elixir, but he wasn't taking it. Now I took out . . . the hand out (pamphlet about morphine) and I talked to him a lot about it. And I talked to him about (how) you don't get addicted if you need it; and how he initially may have some side effects, but they would adjust . . . And it could be that . . . he may have radiotherapy, if that was needed for palliation, . . . then he would probably go down in his dose of morphine afterwards. And I went through all that with him. The District Nurse had already been through it with him. But I am afraid, although I felt I had made contact with him, and we
actually struck a good rapport, ah, I lost the battle in that one. He was very clear that he did not want morphine."

She went on:

"and when I actually looked at him at that stage, I am sure he was denying a lot of the symptoms, but he was actually functioning very well, . . . you can only sow the seeds. . . . I didn't go in there with a big bang, I just sort of sat quietly and talked. . . . but I saw I was getting nowhere fast, so I just sort of left it there. . . . I don't believe you can force people, and I just thought he would choose it when he wanted it. And needed it. So I actually felt OK about him not taking it.

So, my view was that, ideally, it would have been quite good if he had taken some, but it was his choice, and his feeling of control, and that was OK.

You know it is really important for him to call the shots, and I really respect that." Mary 1, p8

I wondered if the family felt the pain management had been handled well in these early days. Michael had already told me a little of the family history and attitudes to Ivan's communications:

"he liked sort of - stretching things. And so we never really took a hell of a lot of notice of him when he moaned and grumbled. Although we looked out for him" Michael, 1. P1

I asked about any similarities in his parents' illnesses.

". . . in terms of similarities, no, the up and down, moods, and that sort of thing were sort of similar. The effects the drugs had on moods were similar. But, no, that is probably where the similarities ended. I guess the fact that both of them also didn't really want to give in to it, wanted to get things sorted out for themselves, didn't really want to just lie back and - let it happen." Michael, 1, p7.

I introduced the pain management issue specifically.

EN "there was a stage when we were aware that he was having pain, and . . . pain was increasing and he was refusing to begin medication. Were you aware of that?"

Michael: "from what we understood . . . he was scared because he had seen what happened to Mum. When she started taking morphine and things, and started to lose control of her thoughts. . . . And started the mood cycling and all the rest of it. I think he was quite scared. He didn't want to let that happen. He didn't want to become reliant on the heavier drugs. And he didn't want to lose control of what he was doing and thinking. That was the way I saw it. And yeah, he did hold out for quite some time. . . . he had seen it before, and he didn't want to . . . he still had too much to do."

EN "from the health professionals point of view, we would have preferred for him to start on pain relief earlier . . . do you think we should have encouraged him to start it sooner, because he was in pain . . . ."
Michael: "you would never – he would never have done it! If he didn't want to do anything, he wouldn't do it. He would never – well it was very, very rare that anyone could actually tell him what to do. Ah, he was one of those people that always believed he knew best. Nobody would have ever been able to have told him to do something that he didn't want to do."

Michael, 1, p9

I wondered what Michael thought of the 'control' issues, and asked him:

EN: "who was in charge of Ivan? Who was responsible for him?"

Michael: 'he was in charge of himself. Yeah. He would never let anybody walk all over him. Or direct him. It just wouldn't happen. Although, he opened up a lot, and - and let us know, for probably the first time in his life that he was actually, ah, more reliant on us than he had ever needed to be... He had never – he had always taken charge of himself, and been accountable for his own."

MAKING SENSE OF THE DATA

The phenomenological approach is a field so large and diverse I cannot present it in a true or meaningful way at this type of forum. I will ask you to accept that its corner stones are: one - an intense focus on and reverence for the phenomena themselves; and two, the work has the purpose of understanding the phenomena.

The seven steps of the method offered by Spiegelberg (1994) entail a minute examination of the phenomenon before formal interpretation. As the very first step encompasses items such as comparing with related phenomenon, identifying similarities and differences, and what do we feel/think about the phenomenon, our own experience and reality are acknowledged at the outset. I think that as with any formal examination, we have at our disposal a number of steps, in which our professional judgment as a researcher will guide the choice. A new researcher may use more steps than needed, but using them will teach her when to use or not use them in future. The more experienced researcher may move more confidently and rapidly to interpretation, having done much of the exploration during data gathering and recording.

As I have read out the texts of my interviews, you will have been intuiting, analysing and forming a picture. You may have asked yourself: what is the main issue here? And: in what ways does it connect with other issues which you see as related? You may have thought about the differing ways the three people reported the same experience. You may be putting together in your mind a composite structure of what is happening; you may be questioning its existence; and finally asking yourself: what does it mean?

These are Spiegelberg's steps in a nutshell. He is cautious about a single focus on hermeneutic interpretation, recommending that we put effort into knowing the phenomenon first, and make our processes of interpretation more apparent. For me, the process has a circularity about it, as we sift deeper on each encounter with the data, informed by our previous work. The hermeneutic circle is both part of the exploration and the interpretation.

An initial encounter with the (very selected) data I have presented suggests to me the following tentative first impressions.
So what is Ivan saying? He is saying that it is the significance of the pain that is more important than the physical experience of pain. The pain reminds him that he is alive, and allows him to know himself. It is a means of communicating the growing seriousness of his illness to his family. To begin morphine risks these important features. He fears he will lose control of his faculties.

What is Mary saying? She is saying that she recognises that Ivan is in pain and would probably be better with morphine, but that he is actually in quite good condition. She thinks the most important thing is for him to decide for himself when he commences on morphine. She believes she can offer expertise, and Ivan can choose whether to accept it or not. Mary talks of Ivan being in control and calling the shots. She recognises that the longer term relationship is at risk if she attempts to force him to do something he is not ready to do.

What is Michael saying? Michael is saying that to his father being in control has always been of paramount importance. He is saying that it would have been a waste of time to try to force him to begin the morphine before he was ready. He offers some understanding in relating it back to how his mother was when taking morphine.

A NARRATIVE APPROACH
Brody (1987) examines the place of narrative in health-illness related events. Narrative allows the individual to self interpret and communicate, though the actual crystallisation into words puts a boundary or limit on the experience. To examine narrative we need to identify the account of events, the feelings and perceptions of the narrator, the emotions accompanying the story and the record, the meaning for the narrator, metaphor used and the missing data.

Together the narratives are relatively synchronous at this point. They show a mutual understanding and tolerance. Both Mary and Michael recognise that for Ivan, being in control is the most important thing to him, even though they do not understand the full significance of analgesia and self identity for Ivan.

This may be seen as a tension between autonomy and connectedness. Though they live their lives in a caring connectedness, yet autonomy prevails as the prime value in this instance. There is shared meaning and internal congruence.

Once he begins MST, the feared parasite, the morphine, has become symbiotic, and he cannot see the world free of its contaminating influence: it is part of him. He recognises only dimly the pre-morphine Ivan, and struggles to remember the fears it held. Mary and Michael do not enter this particular world, though they have their own partial understandings of what is happening.

This may be seen as the tension between the narrative reported and the narrative experienced. Each perspective is a part, a facet of the whole: none complete on its own. This interpretation is more tentative, as Ivan is less expressive about it, and it is not perceived by Mary and Michael.
WHAT IS THE PLACE OF METAPHOR IN THIS DATA

Whether metaphor creates a new reality for us or reinforces and restates an older one, Hawkes says (1972), it has "an immediacy and a vitality that mocks all such reductive explanations of the process" (p93)

Ivan tells me there is no court of appeal for this sentence. This powerful metaphor suggests his awareness that he will eventually relinquish control. His fears of the morphine are expressed as 'doped to my eyebrows', being drunk and seeing hallucinations. These underline the loss of control he anticipates once he is on morphine.

Although Mary uses a strong metaphor of 'battle' when she first outlines the discussion about commencing morphine, this is negated by her later use of 'sowing seeds' (used three times), not going in with a big bang, walking alongside, going with the flow, and letting Ivan call the shots.

Michael describes his father's pattern of 'stretching things', noting that the family 'looked out for him'. He reports that his father would not 'lie back and let it happen', that he wouldn't want to lose control or become dependent on drugs.

These metaphors support the claim for the thread of respect for Ivan's need to control his life. Metaphor can indicate a sub-text which may vary from the overt text, but in this case the congruence is plain.

I don't want to crystallise too much into words or concepts at this point, as I see that this data must be spiraled in from another point. It must also be examined with other phenomena from this set of people. And then viewed with the other 'sets' of people in my study. It would therefore be premature to 'name' or categorise too much. If I see patterns I can pencil them in smoke.

My edited version of Ivan's poem is:

INVITATION TO THE LAST WALTZ

We are old acquaintances, you and I, We have danced many times to life's airs: You daring and bold, I always eluding, As constant your chase, and futile my race.

No promissory notes, no bargains struck, Half measures are not for my pal: Yet peace at the last could be mine If I yield to your dark, cold embrace.

O, oft have I cheated you, kept you at bay, As I lived for those whom I've loved: But jealous you snatched them ever away, Your greed without passion or pity.

The need for my loving is done, Those who care for me are few; I stand in the ballroom alone
Life's melody shocking and shrill.

The rhythm of dance arouses me still,
But no partner to sweep into step,
None to adore, be adored,
And wasted the strength of my arms.

And now I see you return,
Our dance is beginning again.
Your kiss I'll no longer evade
Nor its promise of balm for my pain.

So, my old adversary, into my arms,
Without orchestra, quartet or band,
Whistle the tune, give me your hand,
And waltz me through shadows to peace.