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ESSAY/PERSONAL REFLECTIONS

Dying to talk: Unsettling assumptions toward research with patients at the end of life

KATHLEEN MCLOUGHLIN, B.A.(HONS.)

Milford Care Centre, Castletroy, Limerick, County Limerick, Ireland and Department of Psychology, National University of Ireland, Maynooth, County Kildare, Ireland

> "If you really want to. . .experience what it is like to have a very limited time to live, sit with. . .dying patients and listen."
>
> (Kubler Ross, 1970a, p. 157)

Following in the steps of researchers such as Saunders (1958), Kubler Ross (1970b) and, more recently, Donnelly and Donnelly (2009), I wanted to learn by listening to the patient. I wanted to hear the patient's story to enable me to understand how they felt about their transition to palliative care services and how they saw their future. While similar in my intention to these visionary researchers, I was unquestionably different. With a background in mental health research and quality and risk, my interest in research of this nature was questioned by some ethics committees and viewed with an air of suspicion by some health professionals working in palliative care. As a non-practitioner, was it ethical for health professionals who seek to protect their patients, to allow me to ask the dying what it is like to die?

I am not alone in this situation. There seems to be *"something ethically unique and uniquely challenging"* (Casarett, 2000) about palliative care research and indeed such challenges are well documented (Jordhoy et al., 1999; de Raeve, 1994). However, this raises questions about whether or not health professionals now need to critically reflect on their attitude to conducting research with patients receiving palliative care. What assumptions do health professionals make about narrative research with the dying and what evidence is available that might prompt reconstruction of these assumptions? What assumptions did I have, as an eager researcher working outside the clinical field, regarding my capacity to engage with the dying? What can we learn by listening. . .to the patient. . .the researchers. . .ourselves? Loosely drawing on Fook's (2007) model I seek to examine these assumptions by critically reflecting on my experience negotiating access to, and eventually talking to, palliative care patients. This essay adds to a body of similar literature (Cannan, 1989; Kellehear, 1989; Young & Lee, 1996) whereby the researcher stands back and tries to make sense of their experience, both to enable personal and professional growth and also to inform those contemplating undertaking research in a particular area, of the potential challenges that only experience can reveal. As Bell and Newby (1977) highlight, such accounts of the fieldwork involved in research are "at least as valuable, both to students . . . and its practitioners, as the exhortations to be found in the much more common textbooks on methodology" (p. 9).

I have often been asked how and why I came to be in palliative care. There is often an assumption that there is a deep rooted reason for people to embark on their work with the dying. Was it because of a positive or negative personal experience with death and dying in my own life? Or maybe a spiritual calling of some nature? I can honestly say that none of these reasons brought me to my research and my story is quite mundane and uninspiring. At the time I was working as a researcher for mental health in a clinical audit and research service. I was asked to become involved in a palliative care needs assessment as a researcher to aid the completion of the work within a defined timeframe. I am ashamed to admit that my understanding of palliative care as I commenced this involvement was limited, to say the least, and I recall well the day I sat at my desk and Googled the term "palliative care." As the needs assessment continued, my interest in the area grew significantly and I was particularly concerned that the high level of fear and stigma associated with palliative care

Address correspondence and reprint requests to: Kathleen McLoughlin, Milford Care Centre, Castletroy, Limerick, Ireland. E-mail: kemcloughlin@gmail.com

could impact upon transition to the service. I then began my journey to construct a research question exploring attitudes toward palliative care and the potential impact of health promoting palliative care (Kellehear, 1999) from a constructivist perspective (Kelly, 1955). This question formed the basis of a doctoral study in psychology. To answer my question, I needed to talk to patients receiving the service and this is where my story begins.

In the first region where I attempted to gain access to patients, the ethics committee passed my proposal without question. I then invited a group of palliative care home care nurses to a meeting to discuss my research and to initiate the referral process to the study. As I spoke, I saw a sea of faces looking interested but slightly apprehensive. No one expressed any immediate discontent. It was one week later, as I sat eagerly waiting for the phone to ring, that the call came to say "No, we don't think it is appropriate." The conversation continued and I was advised that because of the absence of a Consultant in Palliative Medicine working in the region, the palliative care nurses did not feel they had the power to make the decision to allow me to continue.

There are many assumptions inherent in this scenario. As a researcher, I had made an assumption whereby I believed that securing ethical approval was enough to grant me the key to the gateway of palliative care research. I was wrong. The literature acknowledges this gate-keeping by clinicians (and others) as a recognized and understandable barrier to gaining access to patients for palliative care research (Ewing et al., 2004; Steinhauser et al., 2006). It can manifest when clinicians "filter" patients who may be appropriate for a study based on their personal interpretations of the study, or on the dying patient's perceived potential willingness to participate, thus affecting the representativeness of the study. Gate-keeping may also occur where there is a protective urge toward the vulnerable (White & Hardy, 2008). This, in turn, gives rise to further assumptions whereby clinicians may assume that their personal interpretation of the study is true, and the assumption that dying patients are vulnerable and may be unwilling to participate in research.

I will now endeavor to unsettle these assumptions. I had assumed the ethics committee to be at the pinnacle of the "power tower"; once they granted approval, the gates would automatically open. I, probably subconsciously, upon their approval of the study, shifted the power I perceived them to have onto myself, assuming that all that there was left to do was to communicate my intentions and watch the referrals roll in. This was not the case and the power shifted to the nurses who, in turn, used the absence of power from medical colleagues as the reason to halt my study in its tracks. I have also discovered since then, that it can be equally as difficult for doctors to conduct research with this patient group. But where should the power really lie? I believe that it needs to lie with the patient.

I recall a day when I had finally gained access to patients. I entered the ward and introduced myself to the potential research participant who apologized that she was unable to keep her appointment because her son was coming to visit with her dog, so she requested I come back the following day. As I made my way out, another patient said "Who's she?" The woman explained that I was doing some research. The other patient called me back and quizzed me about the research, saying I could interview her there and then. When I explained that that would not be possible as there was a procedure to follow, and that if she was interested she could mention it to her doctor, she proceeded to ask me if she had a right to decide whether or not she wanted to talk to me. Under Article 19 of the Human Declaration of Human Rights "Everyone has the right to freedom of opinion and expression; this right includes freedom to hold opinions without interference and to seek, receive and impart information and ideas through any media and regardless of frontiers" (United Nations, 1948), therefore it would appear that she did. As researchers and health professionals, perhaps we need to give patients the opportunity to exercise this right. Perhaps we should allow patients a choice. Perhaps we should detach our perception of the truth regarding the appropriateness for others of a research study and allow the dying patient "to speak, to be a voice for the voiceless" (Monroe, 2003).

I moved my fieldwork to a different region of the country and addressed the concerns of the nurses previously, by enlisting the support of a consultant in my quest to access patients. Ethical approval was not transferable across health board districts, and on re-application in this second region, the second ethics committee made a number of recommendations, through which I navigated for almost a year. I had made an assumption that this ethics committee would approve the proposal in the same manner as the first. Again, my assumption was wrong. This leads me to suggest that ethics committees, regardless of their jurisdiction, might need to work to the same criteria when reviewing palliative care research projects and that it may also be useful to develop evidence-based guidelines for ethics committees to assist them in their decision making around research in palliative care. Casarett (2000) welcomes the Institutional Review Board recommendations (http://www.nih.gov/grants/oprr/irb) that each ethics committee in the United States should have at least one member experienced in the care of people

at the end of life; it also calls for further considerations to ensure that the person is familiar with palliative care research and the nature of palliative care, including the often frank discussions about death and dying that occur in this discipline between health professionals and patients.

I attended the ethics committee meeting where the project was reviewed and I was asked how I intended to ensure that there would be no undue distress for the patient during my study. I was advised that the decision-making capacity of senior clinicians to determine who should and should not be asked to take part in this study was not sufficient to reduce the risk of recruiting participants who may be experiencing high levels of psychological distress. Psychological screening was therefore required at the time of initial referral by the doctor to the study and again upon meeting with the patient at the time of research. The ethics committee had made a number of assumptions in this decision. They assumed that: (1) my research might cause undue distress to the patient; (2) the decision of clinicians to advise (or not) the patient about the study was inadequate; (3) psychological tools would screen out the patients who were likely to be adversely affected by my questions; (4) doctors had the time to administer and score these tools prior to taking more time to discuss the research; and (5) I, as the researcher, had sufficient expertise to tactfully exclude a patient who, on the day of interview, scored in excess of the set limits for anxiety and distress.

As I unsettle these assumptions, I recall a doctor saying to me "The first rule of medicine is to do no harm and I not convinced that we should be asking patients what it is like to die." I found this rather peculiar, coming as it did from a doctor working in palliative care. Surely understanding the answer to this question is at the root of palliative care? Knowing the answer will enable the physical, social, and psychological needs of the patient to be met — is that not the goal of the discipline? Are we feeding a "conspiracy of silence" (Kubler-Ross, 1970)? I understand the absolute commitment of physicians to do no harm and do not take this commitment lightly, but, I am yet to find evidence to support the assumption that narrative research tends to cause undue distress to a consenting patient (indeed this is an area of potential research — Casarett, 2000), however, I have found work to support the view that patients at the end of life benefit from taking part in qualitative research (Cannan, 1989; Hendon & Epting, 1989). Could hesitancy regarding the appropriateness of asking dying people about their experience, reflect an underlying fear of our own death?

Personal Construct Psychology (Kelly, 1955) proposes that human life is about the story each person creates and that human beings like to tell their story, even at the end of life. There may be psychological benefits for the patient in telling that story, particularly to a "stranger," as well as offering a learning opportunity for health professionals and society in general. On one occasion, I presented my research plan to a team of multidisciplinary clinicians working in palliative care and was asked what I would do if someone began to cry as they told their story. Would I stop the interview? Before I could respond, one of their colleagues interjected saying "I think patients will cry as they tell their story, it is only natural from them to show emotion…I don't think it means that the research is distressing them." A debate ensued and it was agreed that I would offer a tissue, demonstrate empathy, and ask them in time, if they were okay to continue. I used a lot of tissues during my interviews with my emotional, but not unduly distressed participants.

The assumption made by the ethics committee in this region that the decision of a clinician to allow a person to partake in the study was not sufficient, was interesting, particularly in the discussion relating to power as outlined earlier in this essay. The ethics committee was now removing the power of the skilled, senior clinician to refer patients to the study and instead handing it over to a paper-based psychometric tool. There are obvious advantages and disadvantages to this action. It eliminated to some degree the potential for clinicians to "filter" patients who may be appropriate for the study based on their personal interpretations of the study and perceived readiness of the patient to participate; and enabled me, as a researcher, to be protected in the event of complaint or adverse incident from a risk management perspective. However, it also assumed that such psychological measures are appropriate and sensitive enough to eliminate those patients who were already anxious and distressed and for whom increasing levels of emotion might not be appropriate. There is no consensus in the literature to inform researchers which tools should be used for this purpose and therefore it may be the case that the decision to refer a patient to a palliative care research study can be informed, but should not be dependent upon, the findings of such measures. However, do doctors have the time or indeed the motivation to be concerned with the research recruitment rates of a doctoral student who is working outside the clinical field? This is commonly recognized as another barrier to referral (Miller & Chibnall, 2003).

A potential risk, presumably, that the ethics committee may not have considered, was the psychological well-being of patients who were deemed to be appropriate and emotionally stable enough to take part in the study on the measure when administered

by the doctor and who then, on attending the research interview, scored in excess of the agreed cut-off point for inclusion and were therefore excluded from the study. Put yourself in the patient's shoes. You have been told about a study and you want to take part. You have arranged to meet with the researcher. You might feel apprehensive, excited, intrigued by this process and delighted at the thought of telling your story. You may have cancelled visitors that day or gone to great lengths to clean your house. You are in the palliative care phase of illness. The aforementioned researcher arrives; you bring out the tea and biscuits and welcome them into your home, your life. Suddenly she says sorry, "you can't take part since the reading on the screening tool was too high." Perhaps the whole anticipation of the research raised your anxiety levels that day and the tool now deemed you psychologically unfit to participate. The psychological repercussions of such a scenario I believe were not considered in the ethics committee's decision making and there was also an assumption that, as a researcher, I would have the skills to inform that person of the decision sensitively without sparking undue concern to them about their own emotional and psychological stability. Following my recent participation in an experiential communication skills training program, I now question whether I did have the skills at that time to deal with that scenario, but thankfully it did not arise with the patients whom I met. In the future, perhaps ethics committees might consider recommending that researchers who are new to palliative care complete some type of communication skills training, undertake introductory courses in palliative care, and read the personal reflections of researchers in palliative care.

The ethics committee then turned their focus to the researcher. They were concerned as to how I would cope with these interviews. This is indeed a valid concern but there are a number of assumptions that need to be explored here. There is an assumption that I am a person who needs to be worried about and there is an assumption that I might not cope with the situation. There is an assumption that this research is different from any other research I have conducted in the past and that these participants may affect me, as a researcher, in a different way from those in other studies. Such assumptions can lead to a defensive reaction by the researcher who may assume that they have the capacity to ensure that they can indeed cope and therefore may take offence or become defensive when subjected to such concerns. I recognize now, as I critically reflect, that I did indeed become a little defensive and indignant about the procedures that were recommended for me; that is, to attend ward rounds and clinics with patients in advance of my study to ensure that I realized what I was actually getting involved in. In the past, I had interviewed groups whom I had considered vulnerable (e.g. the homeless, people who had deliberately self-harmed, cancer patients, agoraphobics, and people experiencing mental illness) so I wondered: are palliative care patients considered more vulnerable that these research populations? Casarett (2000) would argue not. However, I can now see how important this pre-study preparation was both in gaining the trust of the clinical teams and on a personal level to meet patients and have space to consider exactly how I might be affected by the stories I was about to hear. In hindsight, I had a lot to learn (and still do). I would highly recommend that researchers entering palliative care research for the first time make every attempt to obtain such experience in advance of their research encounters. I also cared for myself during the study by keeping a reflective diary, meeting with the clinical teams and supervisors, and recognizing the times when *I* needed to bring out the tissues.

It took almost two years for me to finally meet a patient. I eventually came to find a home for my research in a facility where there was an established culture of qualitative research, in another region, where the third ethics committee I met changed my goalposts again (and incidentally handed decision making back to the clinicians). At the time, I was frustrated by the barriers that seemed to be continually posed to me as a researcher. There were times when I considered giving up and when I began to question my own competence as a non-practitioner engaging in research with patients receiving palliative care. But I can now clearly see where some of the barriers that emerged may have been justified whereas others I still believe to be unwarranted. I wonder now, as a senior member of a management team working in specialist palliative care, if my experiences would be the same - would access to patients have been easier as an "insider"? I suspect it would, but as a non-practitioner, there will always be a possibility that I would be met with a degree of caution as I undertook education and research in palliative care. I wonder too, how ethics committees construe qualitative research with people at the end of life and whether there is a difference between their construction of this group and other groups often perceived to be vulnerable as potential research participants.

Are there other ways to address the ethical issues associated with research with patients receiving palliative care? Could the development of national patient, carer, and public forums in palliative care enable researchers to engage in dialogue with service users to assess the appropriateness of proposed

research designs? Might it be useful for ethics committees to have access to such forums in the future so we can hear, from the service user perspective, whether our questions and procedures are appropriate and safe?

Negotiating through these events has highlighted my commitment to research in palliative care, developed my knowledge of the subject, and given me an understanding of different cultures. Along the journey, I have met dedicated, compassionate people who are passionate about their work in palliative care and the people they care for. But in palliative care "we" need to ensure that we nurture research interest from other disciplines and that we do not deter others from commencing a career in the field.

Incidentally, when I eventually met my first research participant, we were both dying to talk.

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REFERENCES

Bell, C. & Newby, H. (1977). *Doing Sociological Research*. London: George Allen and Unwin.

Cannan, S. (1989). Social research in stressful settings; Difficulties for the sociologist studying the treatment of breast cancer. *Sociology of Health and illness*, *11*, 62–77.

Casarett, D. (2000). Are special ethical guidelines needed for palliative care research? *Journal of Pain and Symptom Management*, *20*, 130–139.

de Raeve, L. (1994). Ethical issues in palliative care research. *Palliative Medicine*, *8*, 298–305.

Donnelly, S.M. & Donnelly, C.N. (2009). The experience of the moment of death in a specialist palliative care unit (SPCU). *Irish Medical Journal*, *102*, 143–146.

Ewing, G., Rogers, M., Barclay, S., et al. (2004). Recruting patients into a primary care based study of palliative care: why is it so difficult? *Palliative Medicine*, *18*, 452–459.

Fook, J. (2007). *Practising Critical Reflection: A Resource Handbook*. Maidenhead: Oxford University Press.

Hendon, M. & Epting, F.R. (1989). A comparison of hopsice patients with other recovering and iltients. *Death Studies*, *13*, 567–578.

Jordhoy, M.S., Kaasa, S., Fayers, P., et al. (1999). Challenges in palliative care research; recruitment, attrition and compliance: Experience from a randomized controlled trial. *Palliative Medicine*, *13*, 299–310.

Kellehear, A. (1989). Ethics and social research. In *Doing Fieldwork: Eight Personal Accounts of Social Research*, Perry, J. (ed.). Geelong: Deakin University Press.

Kellehear, A. (1999). *Health Promoting Palliative Care*. Melbourne: Oxford University Press.

Kelly, G.A. (1955). *The Psychology of Personal Constructs*. New York: Norton.

Kubler Ross, E. (1970a). *On Death and Dying—What the Dying Have to Teach Doctors, Nurses, Clergy and their Own Families.* Kubler Ross, E. (ed.). Oxford: Routledge.

Kubler-Ross, E. (1970b). Psychotherapy for the dying patient. *Current Psychiatric Therapies*, *5*, 110–117.

Miller, D.K. & Chibnall, J.T. (2003). Strategies for recruiting patients into randomised trials of palliative care. *Palliative Medicine*, *17*, 556–557.

Monroe, B. (2003). *Patient Particpation in Palliative Care: A Voice for the Voiceless*. Oxford: Oxford University Press.

Saunders, C. (1958). Dying of cancer. *St. Thomas's Hospital Gazette 56*, 37–47.

Steinhauser, K.E., Clipp, E.C., Hays, J.C., et al. (2006). Identifying, recruiting, and retaining seriously-ill patients and their caregivers in longitudinal research. *Palliative Medicine*, *20*, 745–754.

United Nations. (1948). *The Universal Declaration of Human Rights*. http://www.udhr.org/UDHR/default.htm.

White, C. & Hardy, J.R. (2008). Gatekeeping from palliative care research trials. *Progress in Palliative Care*, *16*, 167–172.

Young & Lee (1996). Fieldworker feelings as data: 'Emotion work' and 'feeling rules' in the first person accounts of sociological fieldwork. In *Health and the Sociology of the Emotions*, James, V. & Gabe, J. (eds.). pp. 97–114. Oxford: Blackwell.