

Three Journeys: The Research Programme of the Palliative and End of Life Care Team at the University of Cambridge.

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Introduction.

The research programme of the Palliative and End of Life Care Team covers a range of discrete topics. Despite the variation and different foci of individual projects, there are a number of linking themes. This short paper considers them. It arises from reflections on the presentations made at the visit of Macmillan Cancer Support visit to the Palliative and End of Life Care Team on 9th November 2018.

Three journeys.

The overarching linking theme is that of the journey. There are three journeys with which we are interested. The journey of the patient or the person who is ill, the journey of the unpaid carer and the family, and the journey of the professionals providing clinical treatments and care. On each of these journeys there are distinct stages, trajectories and chronologies and the progress on the journey takes place for different travellers at different velocities.

Let us first consider the patient and carer / family journeys. There is a significant and relevant literature and some aspects of the journey been very well described over many years – for example the process of bereavement and loss, with such well-known stages as alarm, searching, denial and acceptance (Parkes, 1972) and also descriptions of pathological or morbid grief (Raphael, 1984). Different commentators have developed and described different stages of the journey and the stages they describe and the methods used to elicit the data are informed by a variety of theoretical positions. What they have in common is the idea of progress through, or getting stuck at, particular points on the journey. In the case of anticipating one's own demise, there are various descriptions of the process often with the point of reference being the seminal work of Glaser and Strauss and *Awareness of Dying* (1966). The professional journey has sometimes been described as being linked to the care of particular patients and also classically, in relation to the transitions through various stages of professional socialization. In the literature about professional socialization, the sense of journey concerns that from novice to fully-fledged clinician. The literature about particular patients tends to be found in doctors writing about their own first person experiences (Clarke, 2017). The idea of journey is of the physician or a nurse accompanying someone on all, or more usually part, of the journey (Dzeng, 2018).

The three journeys are obviously related and they interact, as well as being experientially distinct. This is important because particular critical moments or turning points on each path, will not necessarily be shared, or equally critical in a contemporaneous or simultaneous way. It is helpful to remember this and not to assume coterminosity. At its most obvious, the grief of a carer or relative extends after the patient's journey has ended and may continue for many months and even years after that. Although the patient's pathway has ended in a physical, corporeal sense, their social identity lives on in the hearts and minds of those left behind.

The support needs for people on the different journeys will be different. Consequently, interventions designed to help have to be tailored to the specifics of the timetables of each individual journey, not simply imposed, and especially not imposed in a way that assumes the journeys to be coterminous.

There are many pieces of research being undertaken by the group in Cambridge that deal with different aspects of separate journeys. The idea of progress through different stages is common in many of the investigations, as are the cultural and social contexts that are the settings for the journeys.

Some common features of the experience.

What each journey has in common, is that all have four elements related to the ways that the individuals are either facilitated on their journey, or how they will have to cope with the various obstacles and difficulties that arise along the way.

First, to undertake the journey the traveller will require or need to acquire a set of technical skills and competencies. These are very variable. Typically for the patient they may include being able to manage medication and pain, and more generally the specifics of dealing with the ways that bodies change as people move through various stages of illness. Such things as walking, going to the toilet and washing may cease to be things that are routine everyday habitual accomplishments and practices. Even activities like watching the television or accessing the internet may become difficult. For the patient, many or all of the things that they were once able to do physically and cognitively may become, in varying ways, problematic (Strauss et al 1984). For the relative / carer, they may have to acquire new skills such as helping their spouse get in and out of bed, or into the shower, or onto the toilet. They may have to learn how to help someone shave or get dressed. They may have to work much harder to listen, hear and understand what their loved one is saying, if speech, memory and elocution are affected. The traveller may have to learn new techniques, to use aids and to accept help. The learning will apply to both the patient and to the carer / family

(Hoare et al 2019). For the professional, some of the skills they must use are part of everyday practice, and in various parts of their training will more or less have been taught to them. Knowing how and where to deploy the skills involves the skill overlain by judgment and wisdom (Hoare, 2017).

Second, there are very specific interpersonal skills which are necessary as a consequence of the changed circumstances of the relationships between the patient and their family members and their friends. By definition, the relationship between the patient and the carer / relative and the wider circle of family and friends changes in many illnesses, especially in terminal illness. It changes in terms of the assumptions and understandings that exist between people, it changes in terms of reciprocal obligations, and it changes the bonds linking and holding people together (Bury, 2005). The changes require new interpersonal skills and ones that may be hard to acquire just by having to do them. How much support and help is on offer, especially to the relative and carer, to acquire the skills they need? It might be, and often is assumed, that previous social roles, especially of women in families, is sufficient and that men may simply just have to get on with it. These assumptions are probably wide of the mark.

Third, there are very specific intrapersonal skills needed to manage the feelings and emotions that arise as a consequence of having to face up to, or denying, and all the many other different psychological responses, on the journey. The experience of this journey is one that carries a very powerful affective charge, because people's ontological security is undermined; their sense of being in the world and their future place in the world is undermined. Biographies are disrupted and the future is rendered uncertain (Bury, 1982). The effects of this are non-trivial and working through the experiences is something that everyone facing this kind of event will have to deal with. That we normally let people try to work it out on their own is not necessarily an optimal approach.

Finally, there is the question of meaning. All humans endow what they do with meanings and understandings about what they do and the circumstances in which they find themselves. Similarly, all humans are able to articulate reasons for why they do what they do, for what they have done in the past and for they will or might do in in the future. These meanings change profoundly along the journey. The meaning of almost everything has to be constructed anew in relation to the technical skills, the interpersonal relationships and the powerful emotions engendered by the experience (Kelly, 1992a). And meaning is not just something that people create in their heads: meaning is constructed in interactions with others and the parties to these journeys will be involved in more or less conscious accounting for things.

What it is important to remember is that these meanings may be positive or negative, helpful or unhelpful. But whether positive or negative, the meanings which are constructed will be central to

the way that the people involved construct their sense of self; their sense of who and what they are, and their place in the great scheme of things. People's selves are essentially the socially constructed meanings about who and what people think themselves to be, conveyed in the narratives they use to think about and describe themselves. The sense of self is enduring: most conscious adults recognise that they are the same person they were last year, or when they were teenager or when they were a child and certain aspects of their self endure across time, like being a parent, a carpenter, a mother, or a Scotsman. But it is precisely some of these apparently enduring aspects of self that come under greatest threat on the journey. The sense of self is also highly situational in the sense that self reflects things happening in the here and now – being in pain, feeling very unwell, not being able to move and so on - and these have the capacity to flood all other aspects of self and may even blot out the older more enduring aspects of self. The stories and meanings developed along the journey therefore become critical in the way the journey is experienced (Kelly, 1992b; 2015).

Meaning is also central to the way that social identities are constructed. A social identity is the way that other people construct, perceive and define other people as for example as a man, as a patient, as a dying mother or whatever else it might be. As with social selves, identities are also both enduring and situational and on the kinds of journeys we are interested in, the dying identity, although highly situational, may come to dominate the way that others -families and professionals- respond to the patient (Kelly, 2015). Identities are also central to the bereavement process. In the case of the dying person a post-death identity involves others constructing a meaning to a life lived and this may live on after death, in the stories and anecdotes that families will recount of the loved one who has died. While it is quite impossible to deliberately shape the narratives and meanings, it is important to bear in mind that particular types of narrative frame meanings and such framing may be either helpful or a hindrance to coping on the journey.

Inter alia, all of these ideas also apply to professional providing clinical care, but with the important difference that this is not for them a one-off major life event, but rather an ongoing routine part of day-to-day practice and as such is certainly amenable to training or skill development.

Conclusion.

These themes and ideas about the journey and about common elements on the journey are to be found in projects past and present in the research group in Cambridge.

References.

- Bury, M. (1982) Chronic Illness as biographical disruption, *Sociology of Health and Illness*, 4:167-82.
- Bury, M. (2005) *Health and Illness*, Cambridge: Polity.
- Clarke, R. (2017) *Your Life in my Hands: a Junior Doctor's Story*, London: Metro Books.
- Dzeng, E. (2018) Habermasian communication pathologies in do-not resuscitate discussions at the end of life: manipulation as an unintended consequence of an ideology of patient autonomy, *Sociology of Health and Illness*; doi: 10.1111/1467-9566.12825 <https://onlinelibrary-wiley-com.ezp.lib.cam.ac.uk/doi/full/10.1111/1467-9566.12825>
- Glaser, B.G and Strauss, A.L. (1966) *Awareness of Dying*, London: Weidenfeld & Nicolson.
- Hoare S. *Understanding end-of-life admissions: an interview study of patients admitted to a large English hospital shortly before death*. Department of Public Health and Primary Care. University of Cambridge, 2017. http://idiscover.lib.cam.ac.uk/primo-explore/fulldisplay?docid=44CAM_DSPACE1810%2F275055&context=L&vid=44CAM_PROD&lang=en_US&search_scope=SCOP_CAM_ALL&adaptor=Local%20Search%20Engine&tab=cam_lib_coll&query=any,contains,Understanding%20end-of-life%20admissions:%20an%20interview%20study%20of%20patients%20admitted%20to%20a%20large%20English%20hospital%20shortly%20before%20death&sortby=rank&offset=0
- Hoare, S., Kelly, M.P., Barclay, S. Home care and end-of-life hospital admissions: a retrospective interview study, *British Journal of General Practice*. In press
- Kelly, M.P. (1992a) *Colitis*, London: Routledge.
- Kelly, M.P.(1992b) Self, identity and radical surgery *Sociology of Health and Illness*, 14: 390 – 415.
- Kelly, M.P. (2015) Diagnostic categories in autobiographical accounts of illness, *Perspectives in Biology and Medicine*, 58: 89-104.
http://muse.jhu.edu/journals/perspectives_in_biology_and_medicine/v058/58.1.kelly.pdf
- Parkes, C.M. (1972) *Bereavement: Studies of Grief in Adult Life*, Tavistock: London.
- Raphael, B. (1984) *The Anatomy of Bereavement: A Handbook For The Caring Professions*, London: Hutchinson.
- Strauss, A., Corbin, J., Fagerhaugh, S., Glaser, B., Maines, D., Suczec, B., Wiener, C. (1984) *Chronic Illness and the Quality of Life*, 2nd ed, St Louis: Mosby.

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