

From relative to researcher

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“Cancer is not a disease of an individual but impacts the family system.”

(Mystakidou et al., 2002).

Doctor, can you please fix the problem?

In 2016, I was in my final year of training in systemic psychotherapy and I lost my mother to cancer. This story originates from my experience of my mother's illness and treatment, so I will start with that. In March 2016, my mother was diagnosed with a low-level treatable cancer. A treatment plan was initiated swiftly but, in May, she became increasingly unwell and a CT scan revealed metastasis with stage 4 lung cancer. Despite chemotherapy treatment, on 19 July what had been hope became hopelessness, when our consultant oncologist told my mother and me the devastating news that the “*treatment hadn't worked*” and she had just “*weeks to live*”. She passed away on 6 August.

I saw my mother's illness as a life crisis which demanded a re-negotiation of roles and responsibilities within our small family system. After 29 years of being cared for by her, I had become her carer and was required to provide a dual role. When attending hospital appointments, I was the patient's daughter, desperate for our consultant to ‘fix’ the problem and make my mother better. I saw him as the ‘expert’. But, after hospital visits, I would return to work and was required to take my position as the therapist and manage the treatment plan for my patients. I wondered whether my patients also saw me as the ‘expert’ and that I would somehow be able to ‘fix’ their problems. I came to realise that, in the absence of a ‘fix’ or a ‘cure’, it is the relationship, be it the doctor/patient or therapist/patient, which provides the anchor during times of uncertainty.

When I reflect on my mother's illness, I realise that this was not her battle alone but a shared experience and I am the witness to our story. I take the position of an ‘insider’ witness and refer to ‘our’ consultant because, even though my body did not have the cancer, I had an embodied experience which resonated with my mother's pain, suffering and fear, as we both waited for death to arrive.

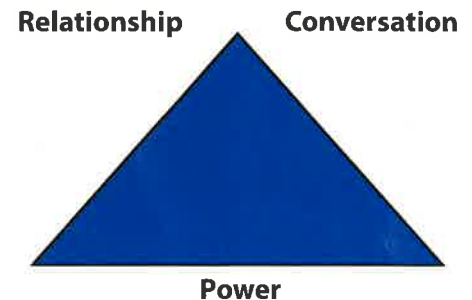
The purpose of writing this article is not only to share a story about an unexpected

and difficult journey of loss but also an experience from which I have gained a great deal of insight, which has influenced my professional practice. I invite the reader to visualise a triangular image which is defined by conversation, relationship and power; these are the three concepts that are at the heart of my article. In my transition from relative to researcher, I have learned that, through initiating a conversation, it creates the possibility for a new relationship to emerge. But that also involves risk taking and, at times, exposing one's vulnerabilities (leading to a perceived loss of power). This is illustrated in the story that follows about my relationship with three doctors; a consultant oncologist, a GP (also trained as a family therapist) and a psychologist (also trained as a psychoanalyst).

Doctor, can we please talk about the death of my mother?

As part of my systemic training, I was required to complete a dissertation. I believe writing to be a helpful way of processing grief and, therefore, I used my lived experience of witnessing the impact of cancer as a stimulus in the selection of my research topic. I considered the academic task as an opportunity to translate a lived experience into a told story. But I wondered whether the act of sharing a personal story would simply invite a sympathetic response or whether it could contribute in a meaningful way, to the field of systemic research. It was only once I started writing I realised the power of storytelling, leading to new possibilities.

Following my mother's death, as a way of processing and coming to terms with it, I wrote to our consultant who was involved in her care. I considered him to also be witness to the illness and, essentially, he went through the experience with us. From my perspective, the moment we met with our consultant, a triangular relationship emerged and the process of co-constructing meaning began. As my mother's illness developed, we each had to respond and re-calibrate. But we were not just dealing



with the reconstruction of meaning but also with the way meaning intersected with the non-negotiable biological changes; crucially when her illness became terminal.

My correspondence with our consultant provided me with an opportunity to begin a process of self-reflection, through which I was able to share with him my thoughts, in relation to what my experience of the doctor/patient/family relationship had been like. It also punctuated for me the start of a more reflective communication between us. From those interactions, coupled with my experience of our medical consultations, I developed an interest in the dialogical process in the doctor-patient relationship and this subsequently became the focus for my dissertation, which attended to the question; *Sharing bad news with terminally ill cancer patients: What does it mean for a physician to deliver news in a sensitive way?*

I shared my intention to write about this topic and requested permission from our consultant to incorporate his correspondence, as part of my work. Despite the ethical implications, particularly in this situation where the clinical relationship is complicated by the legal issues such as, the patient's right to make a formal complaint, or the potential for consultants to allege misrepresentation, I saw his cooperation as an indication of his trust and willingness to engage in dialogue, from which something new may emerge. I considered the sub-textual factors that were at play, namely risk-taking and the shift in power, as I was no longer his patient's relative. I was now the researcher and he (the consultant) was the subject of my research interest. I wondered what

this meant in terms of negotiating the role of the expert, as we moved from a place of certainty to uncertainty.

Building new relationships

For the purpose of my dissertation, I made the choice to conduct secondary research that was comprised of a systematic literature review and a research proposal. While there was not an expectation that I would actually carry out the proposal, having completed my dissertation, it has now led on to the possibility for me to conduct some primary research in the future, within the context of a PhD.

In the early stages of my literature review, I came across the work of John Launer, who is trained both as a GP and family therapist. What attracted me to his work was the focus on “*systemic family medicine*”, which effectively draws on the skills and ideas from family therapy and applies them to primary care (Launer, 2005). I became interested particularly in his communication model “*conversations inviting change*”, which is based on seven core concepts for effective communication; “*conversations, curiosity, contexts, complexity, challenge, caution and care*” (Launer, 2018).

I contacted John Launer and together we considered the potential for developing conversations inviting change within a palliative care context. Significantly, our first telephone call in March 2017 marked for me the start of what I consider to be a mentor/mentee relationship. While this was an unintentional development, it does indeed signify how powerful communication can be in shaping new relationships and enhancing professional growth. Through sharing articles, book chapters and his thoughts with me, the open communication with John has meant I have been able to process my thoughts externally and, on occasions, be challenged about my ideas, benefiting my learning. In addition, he gave me the opportunity to review chapters for his book, *Narrative-Based Practice in Health and Social Care: Conversations Inviting Change* (2018) which enabled me to stretch my thinking and critically evaluate the effectiveness of conversations inviting change across different disciplines, primarily within my work and research contexts.

Discovery

Findings from the literature review revealed that bad news is not always delivered in a sensitive way. The main obstacles identified included time

constraints and work pressures. From a social constructionist position, it can be argued that, when bad or sensitive news is delivered, there will be differences in the meaning attached by the physician and the patient. These key variables will inevitably influence how the physician-patient dynamic co-creates meaning in the narrative of illness.

I was particularly interested in the findings that considered the cultural variances between countries, and how traditions influence rules and procedures relating to giving and withholding information about cancer and prognosis. This raised fundamental questions for me about how language is negotiated within a cultural context around death and dying, and the impact of language used (both verbal and nonverbal) by the physician.

Thinking about this point in relation to the social graces (Burnham, 2012), from the perspective of a British Asian female, I have been brought up within a Hindu religious framework, but as an adult am more spiritual than religious. I hold a belief that significant life events happen at the time they are meant to and I learned from my mother that her illness and subsequent death are life events that must simply be approached with acceptance. Since my mother’s death, spirituality has featured strongly in my life, helping me to make sense of my loss and the subsequent experiences that have been observed by me through that filter of bereavement.

Having made sense of my own experience through a spiritual lens which brought a degree of acceptance and comfort, I was struck by the findings from a BBC article titled “*UK South Asian women hiding cancer because of stigma*” (Haque, 2017); which highlighted the associations of cancer being a “*punishment by God*” and the implications for other family members. As a result of becoming aware of these striking differences in approach within the South Asian culture, I have developed an interest in wanting to understand where spirituality fits, if at all, within those medicalised frameworks that govern how communication happens, particularly when the medic is giving bad news. I have further reflected on how my spiritual belief system positions me as a therapist within a therapeutic setting, when faced with narratives related to illness, mortality and bereavement.

Another significant theme that emerged was the issue of a physician’s discomfort in talking about death and I wondered about

whether this discomfort might be partly rooted in the physician’s own relationship to mortality and, if so, how this might influence their delivery of bad news. Having witnessed my mother’s death, it raised questions for me about my own relationship to illness and mortality. At times, I have found myself in a state of anxiousness, believing that any physical changes I was experiencing were symptoms of cancer, which would eventually become terminal. With time and through deeper reflection, I have started to challenge my anxiety and have come to realise that it is not death itself that frightens me but rather the possibility of becoming ill and the process of suffering while waiting for death to arrive.

A study by Best *et al.* (2014) highlighted the “*expectation for the doctor-patient relationship*”; their findings indicated that, “*all patients wanted a competent doctor they could trust*” and “*appreciated the opportunity to express their fears*” (p. 1143). In order to work with different belief systems and cultural differences, I am of the view that this could be achieved through a systemic approach to conversations, which both acknowledges the stages of illness and death, while also providing a different perspective to death necessarily being a result of medical failure. Crucially, research findings highlighted that, despite an existing number of strategies and models available to health care staff to facilitate more effective end of life conversations, there is an absence of effective training for physicians (Back *et al.*, 2003).

Reversing our roles

Sometimes, we as therapists have to quite literally sit in the ‘other’ chair to take the position of the ‘other’. As part of my ongoing research, I have informally met with several doctors with the intention to better understand from them the obstacles they face in their day-to-day work, which might hinder their ability to communicate effectively or, in some cases, what enables them to communicate well in pressurised environments. There was one such meeting which remains very vivid in my mind and a poignant encounter in my research so far.

At the start of the meeting, the doctor invited me to take his seat, which he referred to as “*the driving seat*” and he sat opposite me, where the patient would usually sit. His strategic intervention to reposition me felt like a familiar manoeuvre and one that I use in my own therapeutic work with patients.

However, within this unfamiliar context, it had an unexpected effect on me and I found myself suddenly in a state of discomfort. To use the doctor's analogy of "driving"; it did indeed remind me of when I was a learner driver, struggling with the gears and constantly stalling! I had previously attempted to imagine what it would be like to take the position of the physician but it was not until I actually exchanged places with this physician, did I feel the uncertainty and, quite frankly, a sense of being overwhelmed! I wondered whether this was what physicians' experience; a sense of uncertainty of what consultations might bring.

As the meeting progressed, I became more at ease in my new position and, through our conversations, I was struck by themes that emerged that resonated with the findings from my literature review. In particular, what struck me was this doctor's view about the standard "ten-minute" consultation. From his perspective, the duration of the consultation should be dependent on the issue brought by the patient, rather than the consultation being governed by time. I considered whether time is the dominant context that makes it seemingly so problematic for doctors to break bad news in a sensitive way or whether lack of time is perhaps a cover-up for emotional distancing and what the researcher Isabel Menzies called "social defences" (Menzies, 1960). Having experienced the uncertainty, I was reminded about the complexity of a physician's task, which requires them to manage their patient's emotional (as well as medical) demands, whilst also attending to their own sense of uncertainty.

Your silence is confusing

As a family therapist, I am in the habit of listening to the stories that my patients bring and, as part of relational reflexivity, where I consider it to be helpful, I share stories about myself and I do not shy away from the questions put to me. But, it is an entirely different experience when facing my psychoanalyst; a tall, white, older male, who doesn't say very much. Sometimes he smiles but generally keeps a neutral face. I have had to learn about my analyst by reading his published work, staring at the books on his shelves and listening to the sounds around me, when there is silence between us. I am realising the power of silence, as a method of communicating.

Sometimes I leave the session feeling frustrated that he has not said very much

and I think we have not made any progress. I wonder then what makes me keep going back. Having reflected on this, I realise that I go back because my analyst gives me permission to grieve in a safe space. He is a witness to my pain, my fears and the loneliness I bring to his room. I know that he is watching me; his look is a 'protective' one, allowing me to feel safe enough to express myself in any way I want, to revisit aspects of my life and make confessions I would not admit to outside of his room. Having taken the position of a therapist within systemic practice and been a patient in psychoanalysis, I am learning to appreciate the differences but it also seems to me that, there are elements of the two which complement each other.

My next chapter

Based on the findings from my dissertation and the gaps identified, I have considered that there is a need for a more systemic approach to end-of-life conversations and, as such, I want to find a way to utilise my skills and bridge the gap between the systemic and medical models. I have put forward my research proposal which seeks to explore the question; What would a training programme need to entail to support physicians to have more effective end of life conversations with patients and their families?

My objective would be to analyse the data gathered and, in a structured way, develop recommendations to provide the basis for the development of a systemic teaching programme, for oncology and palliative care staff, prompting a more relational approach to conversations in this medical setting, underpinned by an understanding of what matters most for the patient and their family at the end-of-life stage of their illness. I believe that a systemic teaching programme, underpinned by the conversations inviting change framework, also has the scope to address and challenge the wider contextual belief systems within health care settings.

Closing thoughts

During the early stages of writing my dissertation, I found myself entirely focused on my experience of the illness and was unable fully to acknowledge 'other witness' statements. But, as my work has developed and through my interactions with doctors, I have had an opportunity to start to challenge my own belief systems about how I think communication should happen and

have started to understand the mindset of others. I also realise that my narrative can only be reflective of one perspective and so I am curious about how each of these doctors might tell this story from their own experience of having been in conversation with me.

References

- Back, A.L., Arnold, R.M., Tulskey, J.A., Baile, W.F. & Fryer-Edwards, K.A. (2003) Art of oncology: Teaching communication skills to medical oncology fellows. *Journal of Clinical Oncology*, 21(12): 2433-2436.
- Best, M., Butow, P. & Olver, I. (2014) The doctor's role in helping dying patients with cancer achieve peace: a qualitative study. *Palliative Medicine*, 28(9): 1139-1145.
- Burnham, J.B. (2012) "Development in social GRRRAAACEEESS: Visible - invisible and voiced-unvoiced. In: I-B., Krause (ed.) *Culture and Reflexivity in Systemic Psychotherapy: Mutual Perspectives*. London: Karnac.
- Haque, A. (2017) UK South Asian women hiding cancer because of stigma. BBC News.
- Launer, J. (2005) Breaking the news. *Postgraduate Medical Journal*, 98(5): 385-386.
- Launer, J. (2018) *Narrative-Based Practice in Health and Social Care: Conversations Inviting Change* (2nd Edition). London: Routledge.
- Menzies, I. (1960) A case-study in the functioning of social systems as a defence against anxiety. *Human Relations*, 13(2): 95-121.
- Mystakidou, K., Parpa, E., Tsilika, E., Kalaidopoulou, O. & Lambros, V. (2002) The families evaluation on management, care and disclosure for terminal stage cancer patients. *BMC. Palliative Care*, 1(1): 3.



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