

“Talk to Me Like I was a Person You Loved”: Including Patients’ Perspectives in Cinemeducation

By Ewan Bowlby

In “cinemeducation”, clips from films featuring illness narratives are used to “help health care providers develop skills in the human dimension of medical practice” (Colt et al., v). Yet this educational strategy could be brought closer to the richness and complexity of real experiences by including patients’ perspectives on the selected clips, giving patients an active role in the education of those who provide their care. Alongside this, expanding cinemeducation to include popular television series, reflecting the increasing cultural prominence of television drama, will ensure that the audiovisual illustrations used are those that are most relevant and relatable to patients. Through analysis of a series of focus groups, I highlight several benefits of the alternative approach to cinemeducation I am proposing. Approved and overseen by the University of St Andrews Research Ethics Committee (UTREC), these focus groups brought together patients and healthcare professionals to discuss scenes of patient-doctor interactions from television dramas. The conversations in the groups illustrated how patients’ responses to the clips can challenge and surprise healthcare professionals. Listening to patients’ commentaries on the clips, healthcare professionals became aware of how patients “see things differently”, alerting them to crucial perspectival factors that influence patients’ interpretations of their encounters with clinicians. Studying these focus groups reveals how audiovisual narratives can support and intensify this collaborative process of discovery, affording a shared space in which mutual understanding can flourish.

Rethinking Cinemeducation

Films have long been recognized as a medium that can further the aims of narrative medicine by encouraging doctors to engage with patients on a personal level. Henri Colt describes film as a “powerful medium” perfectly suited to this task because it “motivates all of our human resources for action: reason, intuition, instinctive response, emotion and affectivity” (ix). This awareness of the power of film to humanize medical issues, complementing clinical expertise by capturing and conveying the affective aspect of encounters with patients, has led to the use of film clips in the education of healthcare professionals (Rosenthal vii). Clips are frequently shown in seminars and conferences on narrative medicine to invite an audience to identify with a fictional patient, supplying didactic case-studies intended to “delicately open the hearts of the evidence-based health-care providers” (Marini 73).

However, although the viability and value of this educational resource is proven, it remains an exercise that takes place in isolation from patients, free from the messiness and complexity associated with dealing directly with unique individuals. Using my personal experiences of illness as an illustrative example, I now explain why it is worth not just watching these clips, but also paying attention to how patients respond to them.

Whilst films featuring illness narratives can “open the hearts” of doctors, their impact on patients can be similarly profound. It was through a process of reflecting on fictional, audiovisual narratives that I came to be able to speak, meaningfully and honestly, about my encounters with clinicians following a cancer diagnosis. Still grappling with the transition to adulthood, I was told that a brain tumor in my right frontal lobe had become cancerous and, whilst treatable, this disease was likely to end my life before I turned thirty. This prognosis was communicated to me in a series of traumatic, disorientating meetings with surgeons, oncologists, and radiographers. Trying to make sense of what I had heard, I was initially forced to resort to “repetition of what the physician had said”, relying on the “medical narrative” to describe experiences that continued to feel alien and impenetrable even in my memory (Frank, *Wounded Storyteller* 5-6).

Serendipity, rather than an active search, introduced me to an alternative narrative framework for understanding and describing my interactions with clinicians: fictional illness narratives in television series. During a year of chemotherapy treatment in which I was frequently reduced to lying listlessly on a sofa, I started to notice a remarkable range of stories appearing on my television screen featuring cancer patients and their oncologists – *Catastrophe*, *The Kominsky Method*, *Breaking Bad*, *Mad Men*, *Fargo*, *Cold Feet*, to name a few. Through watching these audiovisual renderings of the kind of interactions with doctors that had recently altered the course of my life, I began to perceive a framework for interpreting these meetings and gathering them into narrative form. The sparks of recognition and moments of resonance these narratives created crystallized my thoughts and affirmed aspects of my emotional response to these experiences. Alongside this, I witnessed first-hand how fictional narratives can “guide us in thinking seriously about what we seek” (Frank, *Renewal* 9). Increasingly, I found I was inspired to approach my interactions with clinicians in a more purposeful, critical manner, confident of what I wanted to gain from these encounters and aware of why previous meetings had felt unsatisfying and incomplete.

If, as these experiences suggest, audiovisual illness narratives can offer insights to both clinicians and patients searching for a more mutually fulfilling relationship, they could provide the “common denominator” required to harness the “power of narrative as a bridge” (Spiegel and Charon 135). Cinemeducation could become a joint venture. Finding this common denominator would enable the easy flow of storytelling, establishing a shared language. Rita Charon notes that medical professionals must learn to notice when and how narratives are

being told, staying alert to metaphors, imagery, and allusions to other stories (*Narrative Medicine* 66). And if the sights and sounds of television and film could offer a familiar, mutually owned set of descriptive resources, this would help professionals to recognize and contextualize the stories patients told.

Taking patients' responses into account would also ensure that the scenes used were those that patients found accessible and resonant. The selection of illustrative clips should be informed by careful analysis of which forms of audio-visual narrative feel relevant to patients, yet this does not often appear to be the case. For instance, Sarah Rosenthal's study of the use of film in medical ethics focused on the "quality" of films, assuming that those films that had garnered critical acclaim and industry awards would make the most apposite case studies (ix). Judging films based on their critical reception is – in any circumstances – a risky approach, but this is especially problematic when these judgements are determining which films are used to encourage medical students to relate to a patient's perspective. Rosenthal recommends using the film adaptation of Margaret Edson's Pulitzer prize-winning play, *Wit* as a "well-established end of life film" that has won acclaim from critics and healthcare providers and could be used to "demonstrate a variety of nursing ethics themes" (ix). However, the film's protagonist is the literary scholar Vivian Bearing, a somewhat singular, eccentric academic reflecting on her experiences of cancer treatment through John Donne's metaphysical poetry – hardly a relatable, representative character for most patients.

Instead, it seems there would be value in using audiovisual art that has a broader appeal. This is the argument of Desmond O'Neill, who advocates "mainstreaming" the medical humanities by concentrating on "what people are already doing" – on media like popular television – rather than "high art" (O'Neill et al. 111). Without casting the net wider, there is a risk of overlooking influential, accessible narratives that patients are already drawing on when they tell their own stories. It is easy to find popular television dramas featuring illness narratives that resonated with real patients' experiences, such as *Cold Feet* (Shakhnazarova) or *Coronation Street* (Holden), whilst the extent to which these dramas can "speak intimately to personal, emotional and psychological experience" is increasingly apparent (Bainbridge 292). Of course, it is sensible to treat fictional narratives that sometimes resort to "excessive simplification and idealization" with a "healthy skepticism" (Shapiro 25), but these are often also the narratives that help us to find meaning in our experiences. Alongside other people, the popular culture that surrounds us is where we tend to find the structures, imagery and words that become the building blocks of personal narratives. As Frank points out, "most people's poets are the creators of mass-media stories" (*Wounded Storyteller* 200); ignoring what these poets have to say risks allowing practices such as cinemeducation to become detached from narrative frameworks that many patients bring to bear on their experiences, including their interactions with healthcare professionals. Studying the films and television series that shape popular perceptions of these interactions, in

conjunction with patients' commentaries, will reconnect cinemeducation with the forms of meaning-making and storytelling that feel most relevant to patients.

Hearing Patients' Perspectives in Cinemeducation

Theoretically, the reasons for including patients' perspectives in cinemeducation are clear. But it is not enough simply to suggest this *might* prove beneficial, so here I use examples from a series of focus groups to illustrate why this would enhance cinemeducation. These focus groups formed part of a dynamic research collaboration with the Maggie Jencks Cancer Caring Centres Trust (Maggie's) and the Northumberland Cancer Support Group (NCSG), designed to gather evidence of how people affected by cancer respond to illness narratives in mass-media artforms. Audio recordings of the focus groups were transcribed and anonymized to protect participants' identity, and written consent was taken from participants before they took part in the groups. In total, six focus groups were held, with each group involving between five and eight participants. During the groups, participants were shown several clips from popular, mass media films and television series featuring cancer storylines, including several scenes involving interactions between patients and healthcare professionals. Through a process of guided reflection and discussion, those in the groups were invited to comment on the clips in relation to personal experiences of cancer. Every group contained people affected – directly or vicariously – by cancer: patients, friends and family, and also healthcare professionals, so that each discussion revealed differences in how these groups responded to the clips. However, the evidence from the groups also demonstrated how audio-visual narratives can become an entry point into a shared space in which divergent viewpoints can be expressed and debated. Using analysis of the responses elicited by three clips from popular television series featuring patient-clinician interactions: *Orange is the New Black*, *Breaking Bad*, and *Catastrophe*, I draw attention to the insights that listening to the conversations that take place in this shared space can yield.

“Talk to me like I was a person you loved”

The popular Netflix dramedy *Orange is the New Black* features an unusual, thought-provoking meeting between a patient and oncologist, and the discussions of this scene revealed how the same encounter can be seen in a very different light by patients and healthcare professionals. The selected clip shows Rosa Cisneros, a fierce, passionate convicted bank-robber, visiting a hospital as a prisoner, escorted by a warden. Rosa is aware that her condition is untreatable, but instead of telling her the truth about her condition, her oncologist tries to hide behind medical jargon. Rather than passively receiving her prognosis in these terms, Rosa asks for candor and clarity in a typically direct manner: “I don't need any bullshit about percentages, millimeters or stages... talk to me like I was a person you loved” (“We have manners”). This indelicately expressed desire for honesty captures a common concern amongst those experiencing cancer. Rosa's wish to be spoken to in the language of truth, compassion, and

commonality, rather than talked at in terms of “stages or percentages”, speaks to a “cultural and spiritual need for a lost sense of humanity” that many patients will recognize (Marini, vii). Attempting to meet this need, Rosa’s oncologist tries to answer her demands by calmly explaining that she is dying.

The most striking aspect of the discussions of this clip was the dramatic contrast between interpretations offered by patients and healthcare professionals. One patient, who described the scene as showing a “moral dilemma”, was unimpressed by the oncologist’s response to Rosa’s request: “the doctor was speaking in what I thought was sterile language, he wasn’t straight talking or talking to her like she was a feeling person”. They clearly felt that the oncologist had failed to find an alternative to the medical jargon that Rosa had tried to cut through. Several participants echoed this sentiment, with one saying that they could relate to Rosa’s desire for more meaningful communication because, “if it comes over as a sterile conversation you feel like you’re on a production line, as you’re a person, not a cancer patient”. Another built on this point, suggesting there was a parallel between Rosa’s status as a prisoner and her treatment as a patient because – in both instances – she was treated as a “number” instead of a “person”. From this emotive commentary it is clear that Rosa’s appeal to her doctor struck a chord with many of the patients involved, capturing their frustrations and helping them to express their own desire for a more compassionate, humane form of interaction.

However, one healthcare professional offered a strikingly different perspective, that clearly showed how cultural and experiential factors shape the meaning people find in these scenes. Questioning the way that the oncologist had been characterized, they said, “I don’t know if I did think that doctor was sterile from the beginning... he did speak in a soft but clear way, I do think he did speak almost lovingly”. From these comments, the need to consider a range of different perspectives in cinemeducation is evident. Language patients perceived as “sterile” and dehumanizing seemed “soft” and “almost loving” to someone working within the medical professions. This contrast led the participant to try to explain their viewpoint. Saying, “it’s so interesting how you see things differently”, they noted that their profession had determined their response: “I’m here as a health professional, so you do automatically put yourself in there... is there a protection thing where you might want to protect your colleagues?”. Acknowledging that they had instinctively identified with the oncologist, this participant began to analyze the implications of this, undertaking an important process of self-examination that the clip alone would not have precipitated.

“Lung Cancer. Inoperable... do you understand?”

The scene shown from the highly successful HBO crime drama *Breaking Bad* employs the tools of the televisual medium to place the viewer in a cancer patient’s position, as they undergo an

MRI scan then receive their diagnosis. This clip captured a sense of disorientation and denial that resonated with several participants, helping them to convey the emotional, psychological impact of diagnosis, and initiating a discussion that prompted healthcare professionals to consider how to care for a person processing this impact.

In the clip, we see Walter (Walt) White, a father and chemistry teacher who has just collapsed unexpectedly and been rushed to hospital in an ambulance. Immersed in the chaos and confusion, we watch Walt in an MRI scanner, shot from above and upside-down. The camera angle, Walt's bewildered expression and the loud mechanical noises emanating from the machine create an unsettling experience for the viewer, making it easy to share in Walt's anxiety. When he moves into the oncologist's office the noise from the machine is carried over as an extra-diegetic intrusion, ensuring the audience can only hear blurred, incomprehensible speech. Like Walt, the viewer cannot decipher the oncologist's words and the distorting mechanical sounds are only removed in time for us to hear "Lung cancer. Inoperable... do you understand?" Showing no evidence that he has understood this news, Walt can only comment on a mustard stain on the oncologist's tie that has drawn his attention, distracting from the devastating diagnosis that he has just received ("Pilot").

The blurred speech, din and unsettling *mise en scène* were evocative for many people in the focus groups. These effects captured an emotional state that patients recognized – a "panic mode", as one person described it. Others interpreted Walt's behaviour as a dramatic illustration of the difference between hearing and understanding a diagnosis, such as the participant who said Walt's dazed incomprehension reflected their immediate response to diagnosis: "it's like, 'I've got this in an instant, but it's not permeated through me yet'". Describing a similar experience, a patient borrowed the visual metaphor of Walt's strange fascination with the oncologist's tie to explain how their reaction to diagnosis contrasted with their spouse's, saying, "the whole thing seemed to hit her right there and then, whereas I'm still looking at this bit of mustard on a tie [i.e., not processing the news]".

Evidently, the scene provided several participants with audio-visual tools that aided reflection and enriched their storytelling. This was also apparent when a patient likened Walt's behaviour during the scan and meeting to meditation, suggesting the sound and sights "become something different to focus on... you've got the beat [of the MRI machine] to focus on then you've got the mustard spot to focus on". Identifying with Walt, they said "it's how you deal with things sometimes – it's a bit like meditation, allowing your brain to formulate [ideas] when things are too emotional". Several others associated themselves with this way of acting, valorizing it as a necessary "coping mechanism", as one participant put it. Furthermore, this commentary led some of the healthcare professionals involved to consider how patients' need for meditation or distraction, buying time to process shocking news, could be accommodated. Having listened to the comments this scene elicited from patients, they recognized the

importance of making allowances for coping mechanisms that may seem strange or irrational. For instance, one clinician suggested that the oncologist could have participated in Walt's "meditation", giving him space to come to terms with his prognosis by participating in his deflection strategy: "you kind of thought [the oncologist] could have said, 'I had a burger for lunch' or something [to explain the mustard stain], but there was just no reaction". Collaboratively, through discussions of the clip, patients and providers appeared to be moving toward a clearer understanding of why this encounter felt unsatisfactory, whilst also testing out alternative approaches to these interactions. One caregiver expressed this perfectly when they said that the clip had encouraged them to consider how to "show a bit of humanness" when interacting with patients, searching for "some kind of connection" with the people they were treating.

"It's sort of next door to cancer"

Sharon Horgan's inventive sitcom *Catastrophe* is about a woman's experiences of the havoc created when a whirlwind romance is complicated by an unplanned pregnancy and an unexpected diagnosis. In the clip that was shown in the focus groups, Sharon (played by Horgan) finds a routine meeting to monitor her pregnancy turning into a traumatic ordeal, as she is told that she has a "pre-cancerous" condition. Yet it was the manner in which this diagnosis was delivered that drew the most attention in the focus groups. Without warning, the doctor suddenly starts speaking about an "abnormality" identified in Sharon's scans: cervical dysplasia, which the doctor describes as a "pre-cancer". Inevitably, Sharon fixates on this unexpected reference to cancer, and her distress is exacerbated when, in trying to explain the condition, the doctor says the word "cancer" many more times: "frankly I hate that it has the word cancer attached to it, but it's sort of next door to cancer". A farcical breakdown in communication ensues, leaving Sharon shocked and bewildered ("Episode 1").

Although this scene is clearly designed for comic effect, there was plenty in it that resonated with patients' experiences. Critiquing the clinician's approach in light of their own experiences of receiving a diagnosis, a patient said that the clinician "should never have mentioned cancer" because "that's all you hear". Many other participants identified with Sharon's inability to see beyond the mention of cancer, including one patient who used a narrative about their meeting with a dermatologist to explain the physical and emotional impact the word can have. They related how, hearing a doctor mention "pre-cancerous cells", you "feel yourself tensing up" as "you're always wary of what they [the clinicians] say". Expanding on this commentary, other patients argued that the clip highlighted a real-world problem with language – a failure, on the part of healthcare professionals, to speak to patients with sensitivity and clarity instead of resorting to specialized terms. One person said that they thought oncologists should have "a wee sort of lesson in speaking to patients, to avoid failings in communication". Whilst such lessons are, of course, part of healthcare professionals' education, it is telling that this was not

the perception of several of the patients involved in the groups. They felt it was important for oncologists to “get their language correct” when delivering a diagnosis, as “they’re doing that three, four times a day” and “it wouldn’t be that hard to gloss up on your language so it’s a bit understandable”. It is this mismatch – between patients’ perceptions of what constitutes comprehensible and “correct” language, and the opaque scientific lexicon that clinicians frequently use – that *Catastrophe* exploits as fertile ground for satire. Yet in doing so, the series also offers a scene that can become the starting point for discussions that will help to correct this mismatch, inviting patients and providers to consider how to move toward mutual understanding.

Not only did patients’ commentary highlight the relevance of this comic narrative to real-world problems, but it also provided evidence for the role that patients believed the clip could play in an educational context. Patients advocated using the clip as a scene that afforded opportunities for learning, including one person who exemplified this when they said,

I think that’s a good learning tool. You could show that in its entirety and you can say to clinicians that this is a comedy, but I’m sure there’s something everybody could learn from that.

This gained support from several patients, who variously suggested that the clip could be used “like a learning tool from a book” in which readers must identify “faults” in a scenario, or that it “could be used to show people how *not* to do things”. The practice of “anti-role modelling” by which learners “reflect on who they want to be as clinicians by contrasting it with that they see on a screen” (Shapiro 24) is already a tried and tested strategy in cinemeducation. However, the capacity for this approach to engage and enlighten students will surely increase when a patient’s voice – promoting a specific clip as a learning tool and explaining why it resonates with their experiences – was heard alongside the clip. In fact, the benefits of including patients’ viewpoints were already apparent in the focus groups, when healthcare professionals were prompted by the discussions to begin imagining ways of “doing that appointment differently”. Informed by patients’ comments about the need for a more considerate, sensitive form of care, one clinician suggested that Sharon should have been given the news about her pre-cancerous condition in a separate appointment, “because it’s something completely different to the pregnancy”. Acknowledging that Sharon “needed to know she had a pre-cancerous condition”, the clinician suggested that a “better way to do that” would have been to deliver this news in a subsequent appointment, when Sharon was not expecting to discuss her pregnancy. In this dynamic, collaborative process of learning, the clip mediates patients’ views on what is going wrong and what is lacking, exposing the gaps in communication clinicians must fill whilst motivating them to search for new ways of speaking to patients that minimize distress and soften the blow of a worrying diagnosis.

Conclusion

The use of films to humanise a theoretical issue is an effective didactic strategy that serves the aims of narrative medicine. My proposal does not seek to replace this strategy, but rather to develop the use of cinemeducation in the formation of healthcare professionals. Including patients' perspectives produces a resource that is more complex, yet also richer and more diverse, and brings the conversations closer to real experiences and unique individuals. Because of this, hearing patients' commentaries alongside watching the clips can enhance clinicians' narrative capacity by preparing them to be surprised and challenged. "Isn't it interesting how you see things differently" – the reaction of one healthcare professional after listening to patients' interpretations of the clip from *Orange is the New Black* – is a phrase that encapsulates the merits of this approach. Clinicians can learn how to show "hospitality" when witnessing patients' narratives by "opening the self to others, including those who would disrupt or demand" (Frank, *Renewal*, 2). Appreciating how patients' interpretations of audio-visual narratives can subvert expectations, requiring assumptions to be set aside, will inevitably help healthcare professionals to develop this generous, attentive hospitality, preparing them for the unpredictability of real-world encounters.

Embracing the power of television will also connect cinemeducation more closely to the realities of life for most patients and care providers. The hold of television dramas on the popular imagination is only increasing, so connecting educational strategies to this medium seems to be a logical, necessary step. The plotlines, characters, dialogue, and imagery television dramas contain often become interpretative lenses through which viewers understand their own experiences, so paying attention to how doctor-patient interactions are portrayed in these series is vital. The focus groups I have analysed here show how effective these portrayals are in drawing out personal narratives, initiating discussions and eliciting profound emotional responses, and this is a power that could be harnessed to drive efforts to build a bridge between patients and those caring for them.

Ethical Approval

The focus group study has been approved and overseen by the University of St Andrews Research Ethics Committee (UTREC) as the official Institutional Review Board for the University of St Andrews, and by the Maggie's UK Lead Psychologist (with portfolio responsibility for research) and NCSG Chairperson (on behalf of the NCSG committee).

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Ewan Bowlby is a doctoral student at the Institute for Theology, Imagination and the Arts (ITIA) in St Andrews. He is researching ways of using mass-media artworks to design new arts-based interventions providing emotional, psychological and spiritual care for cancer patients. This involves using fictional narratives, characters, and imagery to reflect and reframe patients' experiences of living with cancer, helping them to understand and articulate the effect of cancer on their lives. He is developing the impact of his research through an ongoing collaboration with Maggie Jencks Cancer Care Trust (Maggie's) and Northumberland Cancer Support Group (NCSG). Other interests include theological engagement with popular culture, the relationship between theology and humor and the use of narrative form for theological expression.

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