

Making Sense of Healthcare Experiences. An Application of Story-Based Medicine

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INTRODUCTION

This paper uses a patient centric, storytelling methodology to contribute to our understanding of the patient experience. It is particularly focused upon questioning what data, collected through the medium of stories, tells us about the patient experience of healthcare. The value of listening to service users is pivotal to the Experience Based Design (EBD) movement which recognizes the role all users play in developing user-focused healthcare services (Bate and Robert, 2007). In EBD, as more generally, storytelling is a powerful medium for organizing and communicating experiences to others (Bate and Robert 2006). Stories generated may take many forms (Frank, 1991, 1995). Their application to healthcare contexts is particularly valuable as the discourse generated contributes to the ‘person-centered’ care agenda favored in healthcare delivery (Care Quality Council, 2014).

Health has been identified as an essential research priority for the science of service. It is also core to the transformative service research (TSR) agenda (Ostrom et al. 2015). This paper contributes to this research agenda particularly in relation to the service research priorities of: enhancing the service experience; and improving well-being through transformative service. It contributes to our understanding of EBD through listening to the story of one service user as she transitions from curative, to treatable, to palliative and end-of-life care. It is organized as follows. An initial literature review considers the existing approaches to patient experience research. Following a methods section, the story of Ma’am, our central character is detailed. Our discussion examines her story to determine the dominant factors modelling her experiences and how these might be captured in other settings. Conclusions and implications are then presented.

LITERATURE REVIEW

Patient experience data, often inter-changeably described as patient satisfaction data (Batbaatar et al. 2017), exists at both an individual level and collective level. It is collected through many different mediums such as traditional survey type tools: Hulka Patient Satisfaction with Medical Care Survey; and Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) survey for instance, along with methods of descriptive feedback: interviews, critical incident techniques, patient narratives and observation for instance. Whilst survey instruments dominate, there is an appetite for, and appreciation of, the role qualitative research methods also play in understanding experiences. Finding ways of effectively deploying such methods, cognizant of their resource implications, is a recurring question (Health Foundation, 2013).

Hospital settings are frequently referenced in patient experience research (Mosadeghrad, 2014). Data collected in studies can be differentiated by in-patient and outpatient experiences (Beattie et al. 2014). Primary care has been extensively covered with studies detailed here indicative of the wider field of research. Greco, Brownlea and McGovern, (2001) examined the impacts and implications of different models of systematic patient feedback on the development of General Practitioner (GP) (akin to a Primary Care Physician (PCP)) interpersonal skills. European perspectives are offered by the work of Grol et al. (1990) who identified aspects of general practice that are generally evaluated by patients in a positive way. This included keeping records confidential, GP listening to patients, consultation times and services in case of urgent problems. Where patients struggled to understand organizational aspects scores were higher in fee-for-service systems.

Whilst widespread application of different tools is evident, researchers and practitioners are increasingly questioning whether meaningful data, capable of contributing to the “uplifting changes” in patient care, so central to the TSR agenda (Anderson and Ostrom, 2015, 243), is being generated. A common conflict emerging revolves around what to do with the data generated. Undertaking a systematic review of patient satisfaction literature, Batbaatar et al. (2017) concluded that despite being extensively studied since the 1960s, literature has failed to produce a satisfactory framework to enable a deeper understanding of patient satisfaction. Observable is the tendency for data to be collected where it can be quantified, ‘How quickly were you seen? ‘On a scale of ... how well does your practice ...’ question areas commonly recurring. Such practices has led to Wellings (2015) and others (Wensing, Vingerhoets and Grol 2003; InHealth, 2015) questioning “we have to ask ourselves, to what level are we just good at measuring things, but not good at doing something with all that data?”

Adopting EBD processes offer one mechanism for making data collected meaningful. This approach, grounded in design science thinking, “is not just about being more patient-centered or promoting greater patient participation. It goes much further than this, placing the experience goals of patients and users at the center of the design process and on the same footing as process and clinical goals” (Bate and Robert, 2006, 307). It is a user-focused design process intent upon uncovering key moments (moments of truth) and places (touchpoints) where subjective experience is shaped. Storytelling is pivotal to the process due to its capacity to introduce empathy, what works, what does not work and why into conversations (Charon, 2006). Storytelling bears witness to close and often personal or observable contact with systems (Hurwitz, Greenhalgh and Skultans, 2004). In so doing it offers a window onto not only the ‘*what needs changing*’, but also the ‘*how*’ it might change.

Storytelling is informed by narrative theory which argues that most information stored and retrieved from memory is episodic. Encouraging people to tell their stories is an effective way to incite incidents, experiences, and evaluations. It allows people to share with the researcher *their* experiences, as opposed to the researcher imposing their beliefs in the form of predetermined interview or survey questions. The power of stories and storytelling lies in their capacity to achieve a deep understanding of consumers (Woodside, Sood, and Miller 2008).

METHOD

Research Design: Storytelling techniques were adopted for this study. Frank (1991) suggests four broad genres of stories exist: restitution; tragedy; quest; and chaos. This study is housed in the ‘tragedy’ genre: “The patient-hero struggles unsuccessfully to survive and be heard in the face of medical incompetence or insensitivity”. This genre illuminates the practical and moral tensions which are embedded within the patient experience. Storytelling has been applied in many healthcare contexts (Greenhalgh, 2006), including palliative care where it has been shown to be a humane method of data collection, providing the voice of patients and carers who may otherwise have been unable to participate in research (Gysels, Shipman, and Higginson, 2008; Richardson, 2014).

Data Collection: The story detailed shares the experiences of one cancer patient, Ma’am, captured through the ethnographer’s toolkit of endless jottings, text messages, conversations and scratch notes (Atkinson et al. 2001). As a former Royal Air Force (RAF) non-commissioned officer Ma’am was used to rapid ascents. However her rapid ascent at the age of forty-five into the world of illness, “aggressive cancer” no less, took her completely by surprise. It began without warning in the summer of 2013 and ended, with equally little warning, in the winter of 2014. During this time she became a frequent healthcare flyer, moving between primary, acute and community care, at times on a daily basis, before spending her final hours in palliative care. In this world her operations, now named “procedures”, revolved around the removal of lymph glands, the unstable insertion of tubes, stents and other

interventions, and extensive radiotherapy executed on a daily basis for a period of two months. Explained, well intentioned, and “necessary” actions, the outcome of the treatment regime incapacitated Ma’am, stripping quality from her life in the process.

Data Analysis With space constraints, only parts of the story can be shared here. In essence this represents a “selective representation of the key [dominant] themes and issues” (Palmer, 2005, 12) emerging within the parameters set by the research questions. Manual analysis has been applied to preserve the richness of the data.

FINDINGS

In this section we provide excerpts from Ma’am’s story. These are illustrated through the quotations included in Table 1. We begin the story in the final weeks of her life. She is on the phone to us, telling us about her latest clinical encounter with a senior oncologist, one of the many clinicians she has had cause to meet in recent times. She does not know him. He is working as part of a team, in a general hospital. At a push she might be able to recall his name, but that would be the exception rather than the rule as so many health professionals she meets do not share this information.

Insert Table 1 about here

She starts by apologizing to us for not successfully “fighting” her cancer, something instilled within her through the “language of warfare” (Sontag, 1983) she has been living with since her diagnosis. She’s explaining to us that this consultant has told her, or rather *‘injected reality’* that the cancer has spread, significantly (Table 1, quote f). What had started out as merkel cell cancer, a rare form of skin cancer, is now presenting as multiple cancers. Treatment is moving from treatable to palliative, end-of-life care. He has shared this information with Ma’am alone, having asked her family, her advocates, to leave the room first. She never recovers from this conversation, or the manner in which it is delivered.

Her treatment regime has resulted in multiple complications including lymphedema and physical impairments. Unwittingly she has become an expert in the ‘patient experience’. She has lived it each day. Yet at no point during this journey has *her* ‘patient experience’ been documented. At no point following this journey was it documented either, her clinical needs always the focus of discussions. For Ma’am the lack of interest in her wider experience suggested the existence of ulterior hidden messages, that she was really facing a death sentence which no-one wanted to document (Table 1, quote d). She was saddened and disconnected when actions which dominated her life appeared to be so inconsequential to others (Table 1, quote b). She continuously questioned the hidden messages periods of inactivity might be indicative of (Table 1, quote e).

She celebrated the episodes of service delight which appeared too during this time. The clinician who took time and trouble to pop by to chat with Ma’am, often, and particularly when he heard her husband had also been admitted to a separate hospital (Table 1, quote c). The healthcare assistant who went the extra mile (Table 1, quote g), and the receptionist who spent time re-arranging treatment slots to specifically accommodate times when Ma’am was least likely to be sick (Table 1, quote a). These actions generated strong feelings of a sense of worth for Ma’am. She felt valued. That her experience did matter.

DISCUSSION

According to The Picker Institute Europe (2009) patients seek: fast access to reliable health advice; effective treatment delivered by trusted professionals; participation in decisions and respect for preferences; clear, comprehensible information and support for self-care; attention to physical and environmental needs; emotional support, empathy and respect;

involvement of, and support for family and carers; and continuity of care and smooth transitions. If this is so, then aside from examples of emotional support, empathy and respect (see Table 1, quotes a, c and g), Ma'am's story highlights many areas that scores would be low when quantified in a patient experience survey, if covered at all. Long periods of waiting for results, incomplete when finally delivered (Table 1, quote b). Interactions with professionals unknown to the patient, providing indigestible information (Table 1, quote f). Lack of continuity or opportunity to transition into different environments (Table 1, quote e). All from the short excerpt provided here.

Articulating these narratives through storytelling has allowed us to benefit from rich descriptions of experiences, whilst at the same time reminding us of the futility of developing data capture systems which measure only planned, expected and intentional actions. Ma'am's story enables us to move away from focusing upon experiences as isolated, almost time specific incidents, one doctor-patient consultation for instance, introducing instead a lens on experiences which cross multiple service settings. It captures insights into multiple issues at once, issues which matter to the patient, not necessarily appearing on a predetermined list. It helps us to shift the conversation and research imperative towards appreciating that different information is needed by different stakeholders, mapping out also who these stakeholders include. In essence, storytelling provides a window into patient lived experiences.

Experiences do not occur in a vacuum and are particularly messy to successfully unpack. Patient experiences perhaps more so as they are really immensely complex experiences of an immensely complex service where "services are dynamic, unfolding over a period of time through a sequence or constellation of events and steps" (Bitner, Ostrom and Morgan, 2007, 3). A visit to a GP/PCP, an outpatient, or inpatient clinic involves multiple actors onstage (eg doctors, nurses, consultants) and backstage (eg pharmacists, laboratory assistants), and multiple service encounters (eg consultation, blood tests, x-rays), in multiple settings (eg surgery, walk-in center, acute care) with multiple agencies (eg NHS, social enterprises). It also includes assessments linked to both human (staff) and non-human (infrastructure) factors. In effect what we are really saying is that it takes place within a service system involving "dynamic configurations of people, technologies, organizations and shared information that create and deliver value to customers, provider and other stakeholders" (IFM and IBM, 2008, 1).

LIMITATIONS AND OPPORTUNITIES

Stories enable us to see this system from multiple vantage points, primary care, acute care etc, appreciating the multiple stakeholders involved too: patients, family; friends; clinicians. They provide important service improvement opportunities for healthcare providers. In this paper these are linked particularly to communication, information dissemination and listening to patient needs. Communicating clearly who staff are, their role, the timeframe for treatment and feedback can instill calmness and understanding into the patient experience, further enhanced where information regarding reasons for periods of inactivity is disseminated. Asking the patient about their concerns, clinical and non-clinical, will alert the professional to the meaning attached to activities. In this story for instance, whilst delayed scan results will likely be an annoyance for healthcare professionals, for the patient, the meaning was far more sinister.

However, stories are by design wordy and resource intensive to collect. Whilst their richness cannot be disputed, the challenge ahead is in crafting them in a manner which meets the threshold of patient experience data needed i.e. systematic and rigorous. As this paper has outlined, EBD provides us with a design science based framework to direct us forward. Seeking ways to capture the key moments (moments of truth) and places (touchpoints) where subjective experience are shaped, central to EBD, needs to lie at the heart of this framework. Researching

the effectiveness of adopting such a framework for data collection provides considerable opportunities for future research.

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Table 1: Narrating the patient experience

Illness Trajectory	Primary Touchpoints	Moments of Truth
Curative	General practice General hospital Specialist cancer hospital Community nursing Phlebotomy	<p>a) "She said [receptionist] not to worry, I always seem to be sick in the morning so she's going to move my radiotherapy slots to later on in the day so I don't miss them".</p> <p>b) "She said [oncologist] she hadn't seen all the scans yet but I've been waiting three months for the feedback on the treatment (...). I thought that was what this appointment was about. (Ma'am).</p> <p>c) "He [doctor] remembered Mark was ill and came especially over to talk to me about him (...) It was so good of him, it</p>

		really cheered me up (...). We chatted about Mark's problems. I feel better about that too". (Ma'am)
Treatable	General practice General hospital Specialist cancer hospital Community nursing Physiotherapy Phlebotomy	<p>d) "...no-one has ever asked me about my experience (...) But if it's [cancer] aggressive, and rare, and how many times have we heard that? then shouldn't they want to know? (...) wouldn't it help them to look after it better? There must just be no hope and they can't face telling me..." (Ma'am).</p> <p>e) "They've told me they are going to try chemotherapy now but I need to go into Danebank [hospice] to build up my strength first (...). There's no bed apparently and I don't know whether I'm next or last on the list (...). Do you think they are trying to tell me something?" (Ma'am).</p>
Palliative/End-of-Life Care	General practice General hospital Community nursing Physiotherapy Phlebotomy Hospice	<p>f) "He [oncologist] told me 'I'm here to inject reality into the situation', I just feel so frightened now" (Ma'am)</p> <p>g) "I've [healthcare assistant] organized a nice bath and I'll bring some nice bubbles in (...) I got some lovely ones for Christmas (...). You'll love them, really lovely smell. The kids are trying to get to them too. I always feel so much more human after a bath, don't you?"</p>

Source: Primary Data