

Exploring the Legacies of Filmed Patient Narratives: The Interpretation and Appropriation of Patient Films by Health Care Staff

Qualitative Health Research
2015, Vol. 25(9) 1241–1250
© The Author(s) 2015 
Reprints and permissions:
sagepub.com/journalsPermissions.nav
DOI: 10.1177/1049732314566329
qhr.sagepub.com


Mary Adams¹, Glenn Robert¹, and Jill Maben¹

Abstract

We trace the legacies of filmed patient narratives that were edited and screened to encourage engagement with a participatory quality improvement project in an acute hospital setting in England. Using Gabriel's theory of "narrative contract," we examine the initial success of the films in establishing common grounds for participatory project and later, and more varied, interpretations of the films. Over time, the films were interpreted by staff as either useful sources of learning by critical reflection, dubious (invalid or unreliable) representations of patient experience, or as "closed" items available as auditable evidence of completed quality improvement work. We find these interpretations of the films to be shaped by the effect of social distance, the differential outcomes of project work, and changing organizational agendas. We consider the wider conditions of patient narrative as a form of quality improvement knowledge with immediate potency and fragile or fluid legitimacy over time.

Keywords

health care, users' experiences; health care, work environment; knowledge construction; research; participatory action research (PAR); quality improvement; stories / storytelling; visual methods

In recent years, a promise that attending to patient stories will help revise or transform the nature of the clinical relationship (Hurwitz, Greenhalgh, & Skultans, 2004; Kleinman, 1988) has been extended to their potential contribution as part of broader health care quality improvement interventions (Bate & Robert, 2007; Donovan & Mercer, 2003; Greenhalgh, Russell, & Swinglehurst, 2005; Iedema, 2011; Wilcock et al., 2003). Such developments have occurred in parallel with an ascending neo-empiricism of new public management that relies on the calculative knowledge practices of audit, benchmarking, and standard setting (Munro, 2005; Strathern, 2000). As a counterpoint to these practices, personal testimony is upheld as having a distinctive value and "feel" because of its capacity to reveal what being a patient is really like (Callanan, 2012; Iedema, 2011).

The idea that hearing personal narratives or stories by patients can encourage critical reflection and lead to change in clinical practice or inform quality improvement work hinges on more enduring struggles in the politics of knowledge and representation in late modern social forms (Benjamin, 1968). As Bruner (1986) argues, telling and hearing stories involve a leaning toward the value of reasoning grounded in human experience and purpose rather

than in generalizable laws. Narrative approaches have been identified as offering a challenge to the essentializing tendencies of the "expert" gaze. They might reduce expert authority to a narrative with no wider claim than any other (Rolfe, 2000); protect against the devaluation of human subjectivity by science (cf. Hurwitz et al., 2004); or challenge the effect of outcomes-driven organizational improvement work at operates at the expense of more humanistic approaches to care (Donovan & Mercer, 2003). Iedema (2011) also highlights the potential for new inductive strategies—including the use of patient stories—to inform quality improvements in situations where clinical or organizational complexity eludes deductive methodologies that rely on reduction by objectification or numerification.

The inclusion of illness or patient testimony stories in health care quality improvement work often involves an

¹King's College London, London, United Kingdom

Corresponding Author:

Mary Adams, National Nursing Research Unit, Florence Nightingale Faculty of Nursing and Midwifery, King's College London, James Clerk Maxwell Building, 57 Waterloo Road, London SE1 8WA, UK.
Email: mary.adams@kcl.ac.uk

assumption or claim that patient narrative, like the narratives of other disempowered or marginalized groups, carries a very particular sort of validity that is rooted in experiential as opposed to more distanced and abstracted forms of knowledge (Abel & Browner, 1998). Knowledge claims made on the grounds of “patient experience” involve a distinctive form of positioned authority that is often presumed to be direct and embodied, raw and honest, and to offer insight into the true “inner” self (Atkinson & Delamont, 2006; Chalfen & Rich, 2007). However, narrative theorists repeatedly remind us that stories are less about the revelation of truth as about the crafting of truth in certain ways (Bruner, 1986). Thus the achievement of a story is always relational—creatively shaped within a certain range of possibilities in the relational dynamics between the teller, tale, and listener (Hurwitz et al., 2004). In this sense, narratives are always produced *in* relationship; they rely on some degree of shared moral orientation between tellers and listeners (Kleinman, 1988) and thus require study as skilled forms of practice that propel and reshape meaning within particular social contexts (Atkinson & Delamont, 2006; Greenhalgh et al., 2005). Thus, in their critical analysis of the varied significance of an online resource of (mostly filmed) illness narratives for patients, Mazanderani, Locock, and Powell (2012) note the need to consider the ways in which the experiences of patients are recognized or overlooked as knowledge sources in different health care contexts.

Our empirical case study examines the ways that filmed patient narratives acquire, and re-acquire, meaning as sources of knowledge for health care quality improvement staff during an action-research, participatory project designed to improve cancer services, and which involved a partnership between staff and patients. We build on Gabriel’s (2004) theory of the “narrative contract” to examine professionals’ initial response to, and later interpretations of, the patient films as legitimate or questionable sources of knowledge for their clinical and organizational work. Gabriel identifies the narrative contract as the usually tacit and ever crucial aspect of any story: the shared agreement between teller and audience of what is possible (meaningful, recognizable, and believable). This agreement regulates “the terms of the narrative or story, the acceptable deviations from documentable reality, the drawing of inferences and making of connections, the legitimate exaggerations and omissions” (Gabriel, 2004, p. 172). Without a narrative contract, a story might be challenged on two possible different grounds: by the “So What?” question, which implies that the story fails to carry shared meaning, and by the “Did It Really?” question, which implies that the story fails to carry verisimilitude. A persuasive narrative, Gabriel reminds

us, rests both on the adherence of tellers to some established forms of representation and on a degree of shared moral orientation between tellers and listeners for it to be recognized as a source of knowledge. Our study explores the fate of filmed patient narratives (“patient films”) as sources of meaningful and reliable knowledge as these were reevaluated by clinical and quality improvement professionals as well as by some patients over a 2-year period. We examine how the first shared orientations toward the films were established (how they acquired legitimacy and believability) and the circumstances in which such orientations were questioned and meaning re-interpreted in the course of time.

Research Context

In 2011 to 2012, we undertook an ethnographic evaluation of the spread and sustainability of an Experience-Based Co-Design (EBCD) quality improvement project that had been implemented, 2 years previously, in breast and lung cancer services within an Integrated Cancer Centre situated in an acute hospital setting in England.

EBCD is a form of participatory action research that aims to capture and understand how people actually experience a process or a service . . . deliberately drawing out the subjective, personal feelings . . . to identify “touch points—key moments that shape a person’s overall experience” (Bate & Robert, 2007, pp. 137-150). EBCD is an increasingly popular method of health service quality improvement. A recent international survey of completed, ongoing, and planned EBCD implementations in health care services found that at least 59 EBCD projects have been implemented across six countries and in a wide range of clinical areas in the past 8 years (Donetto, Tsianakas, & Robert, 2014). The approach involves patients, clinicians, and other service staff working together to identify and implement improvements in experiences of care. A significant aspect of the structured, six-stage EBCD process is the screening of an edited film of patient stories of their care experience for audiences of patients and staff. These films are screened with the intention of “triggering” both an emotional response and the start of a change (co-design) process.

In this particular EBCD project, a 35-minute film (called a patient film) for each service (two breast and one lung cancer service) was compiled by two experienced researchers after 4 months of qualitative data collection. This data collection comprised 219 hours of ethnographic observation and 63 staff interviews as well as 36 filmed unstructured narrative interviews with people who were, or who had been, patients in these services. In total, 23 breast cancer and 13 lung cancer patients were interviewed and filmed; the interviews lasted between 1 and 3 hours, and three 35-minute films

Table 1. Time Frames of EBCD and Evaluation, With Number of Evaluation Interviews.

Services/organizations involved in evaluation	Time between film screenings and evaluation	Time between EBCD Project completion and evaluation	Interviewees
Breast cancer service	23–31 months	11–19 months	4 staff
Lung cancer service	21–29 months	9–11 months	11 staff 4 patients
Hospital quality improvement facilitators	21–31 months	9–19 months	9 staff

Note. EBCD = Experience-Based Co-Design.

were composed (one of lung cancer patient experiences for screening in this service and two of breast cancer patients for screening with two different breast cancer service teams located in different areas of the Integrated Cancer Centre). The composite films comprised narrative clips selected to reflect the key “touch points” of patient care experience that the researchers identified from a thematic analysis of the patient interview transcripts relating to each service. The films were initially screened for patients as part of a facilitated group exercise to enable discussion of emerging issues, and, at a subsequent joint meeting, staff viewed the film for the first time with the patients in attendance. At this meeting, staff and patients together identified joint priorities for improvement and, facilitated by local quality improvement staff, continued a process of co-designing and implementing improvements in these priority areas over the following year (2009–2010). In 2011, an independent ethnographic evaluation of the spread and sustainability of EBCD within, and beyond, the Integrated Cancer Centre was commissioned; the findings presented in this article are drawn from this fieldwork.

Method

Ethical approval was received from King’s College London Research Ethics Sub-Committee (Psychiatry, Nursing and Midwifery /10/11-1119), and permission to conduct research with staff and existing patients was received from the “Research and Development” (R&D) committees of the two hospital trusts. Our 12-month ethnographic evaluation used documentary analysis, observational research, and open-ended, one-to-one audio-recorded interviews with staff and patients, including individuals directly involved in the EBCD project and people who had only encountered the services after the project. The aims of the ethnographic evaluation were to explore whether the EBCD project had led to sustained improvements in the breast and lung cancer services, the dissemination and diffusion of the EBCD methodology within and beyond the Cancer Centre, and the impact of a philosophy of patient-centered and patient-informed care,

within the Cancer Centre. The interviews with staff and patients were intended to ascertain their involvement in, and views of, different stages of the EBCD project; felt changes in patient care as a result of the EBCD work (both perceived successes and disappointments); and possibilities for continuing or extending this work.

Our findings for this study are based on 28 interviews with individuals who had been involved in the EBCD “patient film” screenings and co-design work. These interviewees comprised 4 patients who had used or were continuing to use lung cancer services, 11 clinical or service support staff from lung cancer services, 4 clinical or service support staff from breast cancer services, and 9 quality improvement facilitators (whose work transected various cancer service areas). Our study was unable to include breast cancer patients involved in the EBCD “patient film” and co-design work because they were already participating in research documenting the overall success of the EBCD intervention. In addition, our evaluation study was only able to trace the legacies of two of the three patient films; staff in the second breast cancer service, when a film was screened, considered that the EBCD work (and the subsequent evaluation) was not relevant to their efficiency-driven quality improvement goals. The staff and patient interviews were conducted between 21 months and 31 months after the films were first screened. Table 1 details the services involved in the film production and screening, the time frames between the quality improvement work and our ethnographic evaluation, and the number of interviews conducted.

Detailed thematic analysis of interview transcripts was conducted by Mary Adams under the supervision of Jill Maben; M.A. first undertook general and then more focused readings to identify emergent categories and open codes (Rapley, 2011). For example, codes related to the explicit valuation of films, experience of screening events, and relationship between film and improvement work. Subsequent focused coding included the identification of exceptional events and the search for negative evidence. After the research team had agreed on emergent codes, the relevant data (including exemplar quotations and

exemplar cases) were mapped into tables on Computer Assisted Qualitative Data Analysis Software system by M.A. to facilitate “in case” and “cross case” transcript analysis (between informants and between service areas).

Findings

We found three distinctive social processes—film composition, film screening, and subsequent audience interpretations—which shaped how the “patient films” were configured as meaningful vehicles of quality improvement within cancer services. We also identified a pattern to the various interpretations and appropriation of the “patient films” some 2 years after their first screening within the EBCD project. We consider this set and sub-set of findings below.

Film Composition

The lead researcher’s work of “storying” the “patient film”—constructing a 35-minute “talking heads” film from over 15 hours of unstructured and highly varied personal accounts of illness and care experiences in each service—was onerous, not least because the film production has to accommodate multiple interests. For example, each narrative was structured around the common trope of the patient journey through hospital pathways of care (e.g., from receiving a diagnosis to having chemotherapy to being an in-patient, and through to preparing for home), a perspective central to quality improvement staff involved in the project but not necessarily to all cancer patients (whose interviews often involved wider illness narratives). The themes included in the films consisted of a range of recurrent experiential “touch points” that the researchers had identified as significant events (“high and lows”) in patients’ experiences of care within that service. For each “touch point,” varying patient commentaries had to be accommodated. Thus, a range of patient voices were included within this “care pathways” narrative structure, to enable a variety of perspectives and so that no single perspective or single interviewee dominated the film overall. Nevertheless, the researchers recognized that some interviewees were better able to articulate complex care experiences or had greater “on screen” charisma than others.

In all, the films were composed with an eye to the need for clarity, brevity, and immediate applicability for quality improvement in the cancer services, along with consideration for their aesthetic and emotive appeal. In this respect, as the lead researcher described, the “patient films” were composed as a “trigger” for audience engagement and reflection—a rhetorical product—rather than as a consistent account of informants’ biographies of illness or patient hood.

Film Screenings and First Interpretations by Staff Audiences

All interviewees recalled the powerful emotive effect on staff and patient audiences of viewing the “patient films.” For clinicians, in particular, they provided “a very powerful reminder of why we are doing what we do”; “very moving, a vivid reminder of patient experiences”; and a “resoundingly powerful look into individuals’ lives and experiences with cancer” (V. Tsianakas, personal communication, May 5, 2011); cf. Callanan, 2012, p. 21).

Thus, one senior nurse recalled the remarkable effects of the film screening on galvanizing staff to reconsider their behaviors toward patients:

I think the film was the catalyst to solving the problems. . . . This was the thing that absolutely broke down the wall and made people really see clearly that it had to stop and that people’s attitudes had to change . . . there is something very powerful about film . . . it engages everybody, its’ not just reading things or listening to things. . . . The visual side of it I think is very important.

The effect of the film screenings with staff in lung cancer services was also remembered by specialist nurses as remarkable for pressing their colleagues’ attention toward patients’ views of care:

The film has this effect of just making us just sit up and notice . . . and show[ing] them the true, full experience and the enormity of what it’s like to have lung cancer . . . of what a person goes through.

In this service, several clinicians attributed the emotional impact of the “patient film” to the fact that they had, themselves, provided treatment and care for these people—the effects of “hearing from patients you actually knew” and “knowing that that person is someone you had treated yourself.” Other staff remembered the impact of films screenings with a patient audience, of “[them] actually being there as you were seeing what they thought about the care here.” At the same time, other staff and patients remembered the emotive effects of watching people (known or unknown) tell of their experiences: “It was seeing a patient really . . . seeing them tell their story makes it hard to forget.”

In all, audiences (of quality improvement staff and patients) remembered the film screenings as having a remarkable and transformative effect, particularly on the perspective of clinical staff: It provided a window onto a world of patient experience and increased the motivation for staff and patients to participate in the co-design project.

Later Interpretations by Staff and Patient Audience

When we conducted our ethnographic evaluation, some 2 years after the first patient film screenings as part of the EBCD project, the films had come to carry more complex and contested legacies for former audiences as well as for more recent staff audiences. For some staff (and some former patients), the films continued to be regarded as either valuable media that furnished a window on patients' experiences or as rhetorical tools for uniting people around quality improvement work. However, at other times and in different contexts, the films had become less persuasive portrayals of the experiences of patients. Thematic analysis of the staff and patient interviews indicates three different ways in which the films were reappraised—as ongoing sources of learning by critical reflection, as dubious (invalid or unreliable) representations of care experiences, or as “closed” items available as auditable evidence of completed quality improvement work. These various interpretations of the films were sometimes connected to more tacit struggles over the “ownership” or management of meaning—of the filmed patient narratives, of the composite film product, or of the forms of knowledge generated in their viewing. Responses varied according to the felt successes or disappointments of the quality improvement work.

Patient films as ongoing sources of critical reflection. First, in those situations where people felt able to make the care of patients better, the films continued to be valued, and were sometimes rescreened to other staff teams, as a medium for reflection and moral positioning. This was particularly the case for those senior consultants who were able to secure change, most notably in the ways that they or their clinical teams related to patients. Thus, one senior thoracic physician who carried significant responsibility for the diagnosis of cancers initially informed the lead researcher, “I don't do patient-centered care.” Some of the narrative interviews with patients in this service, and the screened film, highlighted the devastating effects of receiving a lung cancer diagnosis in what felt like a hurried way. Thirteen months after this screening, the same physician remembered the incident.

They showed footage of these patients and they were saying, “Oh yes, I went to a lung cancer clinic and the doctor told me my cancer and he didn't even look at me, he was looking at the [computer] screen” so there was a particular, for instance, focus on the moment they were told they had cancer, which was interesting, and obviously at least as it came across, very important to them in the whole pathway, that particular moment was really critical . . . so that's something that I took away as being important . . . it does make me pause for a moment at that point and think and look

the patient in the eye and just try and measure it and judge it a bit, so I think that was probably quite helpful . . . after ten years of doing this, to just pause and think, “Okay, this bit really matters now” and focusing on that.

In both cancer services, some senior clinicians and quality improvement staff rescreened the films for staff teams that had not been involved in the EBCD project. The rationale for these later screenings was described as the need to alert direct care staff to the need for particular quality improvements that were identified by patients and highlighted in the patient films. Thus, in these second screenings (outside with the EBCD quality improvement project) the films were used to persuade staff to attend to specific quality improvement priorities rather than as heuristic devices to trigger more general reflections toward co-design involving both staff and patients. The response to screening the films shown beyond the end of the formal project was highly varied. A nurse consultant described the emotional impact on later film screenings on operating theater staff in the day surgery unit who were not directly involved in the EBCD project.

They had an audit day and so we had everybody out of “day surgery” [and] in the room, so we showed the film . . . and actually people cried . . . Some of them were visibly shocked by what the patients said . . . and I thought at the time, God . . . we already knew [the film] was powerful, but I thought to see [staff] like that . . . I think if you're a “theater [operating theater] person” you don't see the everyday emotion [of patients].

Two years later, when M.A. visited the day surgery unit to conduct ethnographic observations, she was asked by a senior member of staff whether she had seen the “horror film.” This member of staff recalled how distressing the film had been to her and her junior colleagues to view. She remembered those patient descriptions of feeling confused, isolated, and uncared for and of her staff team remarking that “it just made us look terrible.” There were mixed views and memories of the patient film screening in this clinical area—while senior staff felt that they had addressed quality improvement concerns raised by patients in the film, other staff felt that there was a continued lack of attention to patients' experiences of care. Other staff could not recall seeing the films at all.

Patient films as dubious representations of patient experience. Second, and in those situations where clinicians and managers had been unable to secure the quality improvements identified in the EBCD project, the films were questioned as valid or reliable evidence of patient experiences of care. Either the value of the films (or wider participatory research agenda) or the veracity of the film product itself was brought into question. A thoracic

physician who had been unable to implement some of the service changes that he promised his co-design group (e.g., ensuring the presence of a nurse when “bad news” was broken and the availability of an additional private room for this event) had grown cynical of the emphasis on co-design to improve patient experiences:

It all comes down to who holds the budget . . . that’s the bottom line . . . all these things like private time and ferns in the corridor . . . it’s not realistic . . . it’s all a big consumption of medical time if you stick a doctor and a nurse and a relative and a few more patients in a room and just let them run free for an hour or so and that just consumes a huge amount of time . . . It’s not going to meet the needs of the greatest numbers.

This rationale of “service efficiency,” reckoned by the “needs” of the greatest numbers contrasted to the experience of the individual, was a recurrent theme among those staff who felt that the co-design work had placed unreasonable demands on them and their service.

Another senior physician alluded to the dubious nature of the film as “evidence” for quality improvement work—an issue that was also raised by one service improvement lead with a “bench science” background:

Of course, from a scientific point of view it was a very small number of patients . . . almost by definition they are not going to be representative because they’re alive and most are dead within a year . . . they are a selected group . . . but I know that the patients were interviewed. I’m sure they were because they were videoed.

Although concerns were not raised at the time of the screenings, those quality improvement leads who had found co-design work especially challenging, also raised doubts about the representativeness in the films during the evaluation. One lead, in particular, had grown critical of how the stories of patients were edited, often noting patients’ own views on the unfair and biased choice of “patient clips for the camera”:

There was more about some [patients than others] . . . when you’re making a film it’s down to the editors frankly . . . [with] what you put into a film you can tell many, many different stories with the footage . . . a lot was left on the cutting room floor.

In both service areas, the films often became contested knowledge forms for staff and patients alike. Despite the detailed research (observation and interviews) conducted by two experienced qualitative researchers to identify and represent common “touch points” of patient experience, several nurses, particularly those in lung cancer services, worried that editing had highlighted concerns that were

not critical issues for the many other patients they knew, and one senior physician, along with some patients, began to question the circulation of a “patient owned” film that could affect professional reputations.

An exceptional event that highlights the issue of contentious ownership of knowledge on film concerned one of the thoracic physicians, a quality improvement lead, and a patient participant. After patient interviewees had given their consent to the screening of the film, both within the EBCD project and for other quality improvement work, one manager screened extracts from the film at a trust-wide service review meeting and at a national conference. In these selected extracts, the thoracic physician (whose behavior was not presented in a positive light) was easily identifiable to health trust and conference audiences. This physician, and his colleagues, felt that the circulation of the film beyond the co-design setting constituted a breach of trust by the project team. He felt that professional reputation had been compromised without opportunity to reply. The quality improvement manager, in contrast, felt that the circulation of these film extracts was a legitimate means of persuading senior clinicians to attend more carefully to patient experience issues. Following these expressions of concern, one patient contributor to the film felt that, in retrospect, attention to one woman’s experience of receiving a terrible diagnosis from an apparently uncaring physician might have unduly influenced improvement work in this service: “She was the star of the DVD . . . definitely the star sort of thing . . . [so that] some ideas were picked up more than others.”

Our albeit limited findings of patients’ later interpretations of the film to which they had contributed suggest that they had also begun to question the validity of the film on the grounds of both personal biographic representation and equity of voice. Thus, one patient stressed that “she [the lead researcher] . . . took a lot of film of me and listened to a lot of stuff . . . but out of that they used two minutes . . . and that was it.”

In this second re-interpretation of the significance of the films—the immediate and vitalizing effects of the film had tended to dissolve, and questions were now raised about the relevance or veracity of the issues portrayed, particularly among clinicians and project staff who had not achieved what they hoped from the co-design work. At the same time, however, staff in both services continued to express their support for the EBCD and patient film work because it countered the “dumbing effects of questionnaires” and the “blindness to patients [caused by] heat maps and endless data collection.”

Films as items of evidence of quality improvement. The third and final way in which the films were re-inscribed was in their appropriation by and for those staff within cancer

services that held formal performance management responsibilities. From their perspective, a film—in contrast to the intangible social processes that constituted the wider EBCD project—was both material and evidence to support the wider and often contested directives of change within organizations. There were at least two strands to this management approach to the patient films in relation to quality improvement. These were the use of the films to legitimate various organizational change agendas beyond their original intent (of co-design work) and the use of the films as evidence of organizational change in and of themselves.

First, the films were sometimes identified by general and clinical managers as an ongoing resource for the stimulation of staff reflection and discussion on patient experience apart from, and beyond, the EBCD work for which they were originally designed:

The DVD is a huge resource for us because this is seen as independent work . . . which is good when you are dealing with patient experience . . . because patient experience is everywhere now . . . there's a lot of focus in the organization on this . . . there's more and more of it.

From this perspective, the films promised value that extended beyond the felt benefits of the wider EBCD project. Thus, particular short film clips might be selected and inserted into service change work in ways directed by different improvement managers and at different times to give the “patient experience seal” to new, and sometimes divergent, organizational or clinical directives. Thus, one senior doctor (in an adjoining cancer service) screened a short clip from one patient film to a management audience to strengthen his case for costly changes in the clinical management for one very particular patient group (whose care did not appear as a central issue in the original 35-minute film). In this approach, the films acquired value in providing staff selected items of evidence of patient experience and thus contributed to a diverse series of agendas for organizational change.

Second, the films were sometimes discussed by managers as outputs and evidence rather than as methods or resources for organizational change.

This re-interpretation of the edited films (rather than the original patient narratives) in new public management epistemologies of audit, benchmarking, and standards setting was highlighted during a fieldwork visit to a cancer service area. Here, senior managers told of the benefits of their patient film work, and we eagerly accepted their invitation to “see the patient film.” At this visit, the service manager pulled a folder labeled “Peer Review” from her bulging office shelves and showed “the film”—pristine in its study plastic cover. “This,” she explained, pointing at the DVD case, “this is the film.” She described

the value of this item as vital in “demonstrating that we do patient experience.”

This occasional reduction of patient films into simple (unscreened) outputs—that is, into fixed, enduring, and non-controversial items that evidence “patient experience work”—points toward a wider dilemma in organizational change work when accreditation is of simplified and generalizable outputs rather than of more complex, unpredictable, or contested shifts in values and relationships. Managers were often acutely aware of this tension within the wider EBCD project and of their need to produce stable evidence of outputs. One manager of the patient experience improvement agenda noted that

I was asked about whether we are doing better in the areas where we've done EBCD . . . I said, “No, not necessarily” because it's not as straight forward as that . . . patient experience is a complex ongoing thing.

Another manager, with the same work responsibilities, noted “anything that doesn't impact quickly, I have a bit of a problem with, really, or if it takes a long time it's got to have a really big visible impact.”

Discussion

Gabriel (2004) offers a useful perspective on the tacit contractual conditions that have to underpin the persuasive power of films both in their moment of screening and as they are re-interpreted in different circumstances and over time. In the following two sections, we consider our findings in the light of this narrative contract.

First Interpretations: Editing, Viewing, and the Narrative Contract

In this quality improvement project, as in other projects that employ patient stories as triggers to encourage reflection and reflexive learning (Callanan, 2012; Iedema, 2011), the “patient films” were remembered as powerfully persuasive devices. Our findings suggest a series of interconnected reasons for this.

A recent study of the production of knowledge through stories in the very different context of public enquiries (Ainsworth & Hardy, 2012) shows how this knowledge carries a distinctive authority associated with intimacy, “real communication,” and witness, in contrast to the disinterested and impersonal expertise of statistics. Indeed, as noted, several of our interviewees highlighted this contrast as grounds for supporting the EBCD improvement work overall. More specifically, the films composed in the EBCD project, like the illness narrative films examined by Mazanderani et al. (2012), showed people speaking for themselves, their bodies

and voices serving as important vehicles for the articulation of personal, subjective, and highly emotive experiences. However in the particular case of the EBCD films, this was not about the negotiation of shared identities of illness but about the ascription of individuality to authenticate the composite patient journey through hospital care. In addition, as Carroll, Iedema, and Kerridge (2008) discuss in the use of video-reflective ethnography, film as a visual medium has a particular impact on audiences' capacity for reflexivity. Drawing on MacDonald's thesis on the nature of the visual, they examine effects of the foregrounding/distancing dynamic of viewing, whereby an audience can attend to complexity and intensity from the position of practice and emotive distance.

However, prior to these theoretical considerations of the impact of viewing such films, our findings highlight the social significance of the editorial process to achieve these effects. Thus, we found that many staff interviewed still remembered the privilege of being offered access to what four of them described as "the patient's world," suggesting that the films were understood as offering a direct and unmediated window into the experiences of patients (Chalfen & Rich, 2007). However, as our closer examination of the process of film composition shows, this view of a "patient world" was carefully and necessarily contrived. Indeed, the editorial process involved the sometimes sensitive management of competing narrative possibilities: In Birth's (1990) terms, editing is a matter of conceptual framing that directs thoughts in some ways and limits others. The heavily edited "talking heads" format had impact because of its directness, clarity, and capacity to "chime in" with the felt interests and possibilities of the co-design groups (cf. Carroll et al., 2008). Recent applied visual anthropology studies led by Pink (2011) attend to the processes of film production—as well as editing and screening—as communicative processes that create innovative ways to develop common perspectives and shared interests. Chalfen and Rich (2007) examine how visual narratives gathered from an illness community can be used to broker some common ground between a group of young patients and a medical community that held distinctive and sometimes opposed perspectives on best care. As with the patient films that we examine here, film can interweave a complexity of interests, viewpoints, and expertise in the various social processes of narration, shooting, editing, sponsorship, screening, and distribution (Sunderland & Denny, 2007) and can, at least in some moments, create and sustain a "persuasive narrative on a common scale" (Herzfeld, 2001, p. 296). At this initial screening, our informants recalled, audiences were united in agreement over the veracity and significance of the patient film in informing their forthcoming

co-design work. At least at this time, the film effectively brokered a narrative contract that directed a shared ethical endeavor of service reform.

Later Interpretations: Changed Contexts, Discrepancies, and Breaches

As Dickey notes, "media are not consumed in uninflected spaces . . . [c]onsumption is not limited to the moment of viewing, reading or listening . . . but reconfigured in relation to adjoining activities, experiences and social and political agendas" (Herzfeld, 2001, pp. 308-309). Our findings show that when staff and patients reflected on the value of the films some 2 years after their first screening, the films had acquired more diffuse or contested meanings and valuations. Indeed, Ainsworth and Hardy's (2012) analysis of the relationship between stories and statistical knowledge in public enquiries finds that, while stories of personal experience often carry a distinctive and immediate authority, this sort of authoritative knowledge is most likely to be challenged or marginalized over time. This tendency raises particular questions about the longevity of filmed patient narrative work to operate as a source of collective sense-making for quality improvement work (Greenhalgh et al., 2005) and invites a more general consideration of the re-appreciation of narrative knowledge over space and time.

We found that sometimes—and particularly for those with enduring professional investments in the EBCD project—the films continued to be valued as a heuristic tool to stimulate reflection and building consensus for reform. At other times, and for most frontline staff, the films had acquired more diffuse meanings, either as (largely unsuccessful) representations of biographical knowledge or as (often questionable) general representations of patient experience. These later interpretations of value shifted the terms of the narrative contract as some staff, as well as patients, began to question the veracity of the films: to ask the "Did It Really?" question (Gabriel, 2004). For others, and particularly for those staff charged with implementing quality improvements, the films became readily incorporated into the dominant epistemic of evidence established by audit and accounting. Here, the films were repositioned as "second order operations" (Strathern, 2000), whereby film screenings—situated events that opened questions about patient knowledge and experience—were replaced by film products because these are stable, generalizable, and non-controversial indicators of success for accrediting bodies (Perla & Parry, 2011). While some clinicians framed their frustrations with the EBCD project as further evidence of the erosion of clinical care by the "organizational system" (Jorm, Travaglia, & Iedema, 2007, pp. 237–238), other staff had begun to ascribe the films a different value—as uncritical evidence of health service

audit. In this situation, the value of the films was reinscribed in different terms: The narrative contract was breached as staff began to ask “So What? (What Is This To Me?)” (Gabriel, 2004, pp. 173–174). Ainsworth and Hardy (2012) examine the paradoxical production of narrative knowledge (against statistical knowledge) in contemporary Australian public hearings. They find that although personal stories (unlike statistical evidence) were rarely challenged at the time of telling, these stories were far less durable or stable sources of meaning and argument in the longer term because they were not considered to be proper (reliable and generalizable) facts. The varied and, possibly inevitable, process of revisiting “collective sense-making” in project teams over time is examined by Brown, Stacey, and Nandhakumar (2008). They found that, after participants had worked to reshape diverse or diffuse meanings into a common frame of reference, discrepancies in the meaning of this common frame gradually emerged as each participant appropriated and reframed this work in relation to his or her own particular work identities. This view of informants’ tendencies to reinscribe the value of patient films, and shift the grounds of the narrative contract, in relation to concerns with professional identity and self-efficacy is pertinent to our analysis. As Donovan & Mercer (2003) note, moving into patients’ worlds is emotionally demanding, and not without risk, particularly when the possibilities to alleviate distress are limited.

Conclusion

It has been argued that capturing the lived experiences of ordinary people as patients is necessary for allowing health care professionals to imagine new sorts of relational care practices unburdened by organizational targets and assessments of efficiency (Donovan & Mercer, 2003; Iedema, 2011). Our study examines the skills and conditions required for this “capture” in quality improvement work beyond the immediate reception of the films as critical media that skillfully brokered a “patient perspective.” We find that, when staff felt able to act on the expressed needs of patients, the films retained their authority as distinctive and significant sources of knowledge for quality improvement. However, our study also suggests that there is something inherently fragile, or fluid, about patient narrative as a form of valid knowledge in late modern organizational systems. Indeed, the recent recognition of the potential value of patient narratives in health care organizations resonates with a more general accommodation of experiential, particular, and intimate knowledge by new forms of public authority that require that legitimate governments attend to the experience of ordinary individuals (Ainsworth & Hardy, 2012). In promoting new perspectives on care and clinical

practice, the films stood as an increasingly popular but ever questionable counterpoint to the dominant values of calculative and reductive audit practice with their rhetoric of efficiency and scarcity. At the same time, however, as Ainsworth and Hardy (2012) also note, the plasticity of narrative knowledge makes it useful for many different people and for various ends. It is notable then that 2 years after their viewing, all our informants vividly remembered the films (indeed, many of them simply referred to the much wider EBCD project as “the films”), even though many contested their veracity or significance to service improvement. The enduring impact of any elements of improvement projects is notable in hospital environments with rapid, complex, and often contradictory managed change (Willis, 2010). In this respect, the successful brokerage of patient stories has sustained their legacy as an alternative form of knowledge.

Acknowledgment

We thank the patients and staff who participated in this study for their time and patience and the Board of Trustees of the endowed charitable trust that funded this study.

Authors’ Note

Portions of this article were presented at the “Narrative Future for Health Care” Conference, June 20, 2013, hosted at the Centre for the Humanities and Health, King’s College London, and co-sponsored by the Program in Narrative Medicine, Columbia University, New York.

Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The authors disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This study was supported by an endowed charitable trust attached to a large National Health Service (NHS) trust.

References

- Abel, E., & Browner, C. (1998). Selective compliance with biomedical authority: The uses of experiential knowledge. In M. Lock & P. Kaufert (Eds.), *Pragmatic women and body politics* (pp. 310–326). Cambridge, UK: Cambridge University Press.
- Ainsworth, S., & Hardy, C. (2012). Subjects of inquiry: Statistics, stories and the production of knowledge. *Organization Studies*, 33(12), 1693–1714.
- Atkinson, P., & Delamont, S. (2006). Rescuing narrative from qualitative research. *Narrative Inquiry*, 16(1), 164–172.
- Bate, P., & Robert, G. (2007). *Bringing user experience to healthcare improvement: Concepts, methods and practices of experience-based design*. Oxford, UK: Radcliffe.

- Benjamin, W. (1968). The task of the translator. *Illuminations*, 69.
- Birth, K. K. (1990). Reading and righting the writing of ethnographies. *American Ethnologist*, 19, 549–557.
- Brown, A. D., Stacey, D. P., & Nandhakumar, J. (2008). Making sense of sense-making narratives. *Human Relations*, 61, 1035–1062.
- Bruner, J. (1986). Thought and emotion: Can Humpty Dumpty be put together again? In D. J. Bearison & H. Zimiles (Eds.), *Thought and emotion: Developmental perspectives* (pp. 11–20). Lawrence Erlbaum.
- Callanan, C. (2012). Recording patient stories as an aid to training and service improvement. *Nursing Management*, 19(8), 20–22.
- Carroll, K., Iedema, R., & Kerridge, R. (2008). Reshaping ICU ward round practices using video-reflexive ethnography. *Qualitative Health Research*, 18, 380–390.
- Chalfen, R., & Rich, M. (2007). Combining the applied, the visual and the medical: Patients teaching physicians with visual narratives. In S. Pink (Ed.), *Visual interventions: Applied visual anthropology* (pp. 53–70). New York: Berghahn Books.
- Donetto, S., Tsianakas, V., & Robert, G. (2014). *Using Experience-Based Co-Design (EBCD) to improve the quality of health care: Mapping where we are now and establishing future directions*. London: King's College London. Retrieved from <http://www.kcl.ac.uk/nursing/research/nru/publications/Reports/EBCD-Where-are-we-now-Report.pdf>
- Donovan, T., & Mercer, D. (2003). Onward in my journey: Preparing nurses for a new age of cancer care. *Cancer Nursing*, 26, 400–405.
- Gabriel, Y. (2004). The voice of experience and the voice of the expert—Can they speak to each other? In B. Hurwitz, T. Greenhalgh, & V. Skultans (Eds.), *Narrative research in health and illness* (pp. 168–185). Malden, MA: Blackwell.
- Greenhalgh, T., Russell, J., & Swinglehurst, D. (2005). Narrative methods in quality improvement research. *Quality and Safety in Healthcare*, 14, 443–449.
- Herzfeld, M. (2001). *Anthropology: Theoretical practice in culture and society*. London, England: Blackwell.
- Hurwitz, B., Greenhalgh, T., & Skultans, V. (2004). Introduction. In B. Hurwitz, T. Greenhalgh, & V. Skultans (Eds.), *Narrative research in health and illness* (pp. 1–20). Malden, MA: Blackwell.
- Iedema, R. (2011). Creating safety by strengthening clinicians' capacity for reflexivity. *BMJ Quality & Safety*, 20 (Suppl. 1), i83–i86.
- Jorm, C., Travaglia, J., & Iedema, R. (2007). Why do doctors not engage in the system? In R. Iedema (Eds.), *The dis-course of hospital communication: Tracing complexities in contemporary health care organizations* (pp. 222–243). Hampshire and New York: Palgrave Macmillan.
- Kleinman, A. (1988). *The illness narratives: Suffering, healing and the human condition*. New York: Basic Books.
- Mazanderani, F., Locock, L., & Powell, J. (2012). Being differently the same: The mediation of identity tensions in the sharing of illness experiences. *Social Science & Medicine*, 74, 546–553.
- Munro, R. (2005). Partial organization: Marilyn Strathern and the elicitation of relations. *The Sociological Review*, 53(S1), 245–266.
- Perla, R. J., & Parry, G. J. (2011). The epistemology of quality improvement: It's all Greek. *BMJ Quality & Safety*, 20(Suppl. 1), i24–i27.
- Pink, S. (2011). Images, senses and applications: Engaging visual anthropology. *Visual Anthropology*, 24, 437–454.
- Rapley, T. (2011). Some pragmatics in data analysis. In D. Silverman (Ed.), *Qualitative research* (3rd ed., pp. 273–290). London, England: Sage.
- Rolfe, G. (2000). *Research, truth and authority: Postmodern perspectives on nursing*. London, England: Macmillan.
- Strathern, M. (2000). The tyranny of transparency. *British Educational Research Journal*, 26, 309–321.
- Sunderland, P., & Denny, R. (2007). *Doing anthropology in consumer research*. Walnut Creek, CA: Left Coast Press.
- Wilcock, P. M., Brown, S., Geraint, C., Bateson, J., Carver, J., & Michin, S. (2003). Using patient stories to inspire quality improvement within the NHS Modernization Agency collaborative programmes. *Journal of Clinical Nursing*, 12, 422–430.
- Willis, E. M. (2010). The problem of time in ethnographic health care research. *Qualitative Health Research*, 20, 556–564.

Author Biographies

Mary Adams, PhD, BSc, RGN, RM, PGCHE, is a Research Fellow in the National Nursing Research Unit, King's College London, and a co-convenor of the Association of Social Anthropology, National Network in Applied Anthropology, United Kingdom.

Glenn Robert, PhD, MSc, BA, is Chair in Health Care Quality and Innovation in the National Nursing Research Unit, King's College London.

Jill Maben, OBE, PhD, MSc, BA, RGN, is Director of the National Nursing Research Unit, King's College London.