Experience as evidence: the dialogic construction of health professional knowledge through patient involvement.

Abstract

This paper investigates how healthcare professionals articulate the relationship between patient experience and "evidence", creating hybrid forms of knowledge. We propose a Bakhtinian dialogical framework to theorise this process. Drawing on ethnographic work from patient involvement initiatives in England, we show how patient experiences are re-articulated by professionals who add their own intentions and accents in a dialogical process which incorporates diverse forms of knowledge and the conflicting demands of healthcare services. In this process, patient experiences become useful epistemic commodities, helping professionals to respond to workplace pressures by abstracting experiences from patients' biographies, instrumentalising experiences, and privileging 'disembodied' forms of involvement. Understanding knowledge as relational and hybrid helps move beyond the assumption that there is a clear dichotomy between 'objective science' and 'subjective experience'. This paper illuminates how new knowledge is produced when professionals engage with "lay" patient knowledge, and helps inform the sociology of knowledge production more widely.

Key words: Bakhtin, dialogue, evidence, health, hybrid knowledge, participation, patient experience, patient engagement, patient involvement, patient-professional relationship

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Introduction

Patient experience is increasingly seen as a crucial part of evidence in medicine worldwide (e.g. Institute of Medicine, 2001; Department of Health, 2008; World Health Organization, 2015), yet how it can be integrated with biomedical data is often unclear. The relationship between experience and biomedical evidence raises epistemological questions about the authority of lived experience as a legitimate form of 'objective' knowledge (e.g. Scott, 1991).

Biomedical knowledge is reconcilable with patient experiential knowledge (Callon, 1999; Moscovici and Marková, 2000). For instance, Pols describes forms of knowledge as 'epistemes' (2014: 3), and patients' experiential knowledge can be seen as epistemes in their own right that can shape scientific knowledge (Callon, 1999; Epstein, 1996; Arksey, 1998). This dialectical process can bring about hybridisation, i.e amalgamation of epistemes typically found separately and thought to be incompatible (Latour, 1993) (see also Jovchelovitch, 2007; Keshet, 2010), and produce new forms of knowledge. We explore the possibility of dialogue between the different 'rationalities' contained in knowledge based on a hybrid of lived/embodied illness experiences and biomedical epistemes.

Medical decisions rely on hybrid knowledge that includes and is formed by accumulated clinical experience, biomedical evidence, ethical judgments and healthcare professionals' considerations of the needs of patients (Greenhalgh et al., 2014; Sullivan and MacNaughton, 1996; Greenhalgh, 1999; Rabeharisoa and Bourret, 2009). Hybridity in clinical professionals' knowledge is mentioned in the literature (Waring and Currie, 2009; Keshet, 2010), yet the processes of its social production through professionals engaging with patients have not been examined. To our knowledge there has been no previous study either of how healthcare professionals articulate the relationship between patient experience and evidence in practice, or of the nature of the hybrid forms of knowledge that emerge from this process.

In this paper we explore how professional knowledge is articulated and socially produced in health settings, as professionals balance institutional demands for evidence-based and patient-experience-centred practice. We use ethnographic data from two patient and public involvement (PPI) initiatives in healthcare improvement and health research in the UK to investigate healthcare professionals' attempts to borrow, translate and incorporate patient experiences into their professional knowledge. We draw on the work of Mikhail Bakhtin (1981, 1984, 1986) to illuminate the complex interweaving of 'epistemes' (forms of knowledge) (Pols, 2014) within the dialogic process of knowledge production. We explore how professionals position themselves with respect to the 'polyphony' (Bakhtin, 1984) of perspectives that characterise their work environment and how they amalgamate multiple epistemes including scientific rationality, and affective and experience-based knowledge.

Patient experience as evidence

The growing interest in patient experience as a form of evidence raises ethical questions about how patient experiences are used and re-articulated by others (Mazanderani et al., 2013). Some patient experiences might be excluded from contemporary healthcare, for instance those of women, or of vulnerable members of society (Beresford, 2013). There is also an ongoing debate about the 'commodification' of patient experiences (Mazanderani et al., 2013; Lupton, 2014), which are collected, circulated and used as data for assessing service quality and other commercial purposes,

generating economic forms of value. We have previously raised additional questions about how patients learn to enact the types of experiences that count as legitimate sources of evidence in the context of participatory initiatives (Renedo and Marston, 2011).

In many countries evidence-based medicine (EBM) i.e. 'the conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients' (Sackett et al., 1996: 71) has become a central principle of clinical practice (Greenhalgh et al., 2014; Lambert, 2006). There has been a simultaneous increase in interest in patient experiences (Gergel, 2012), with patient-centredness adopted by government and clinical institutions as a domain of quality in its own right (Institute of Medicine, 2001; Department of Health, 2008). Collecting, measuring and incorporating patient experiences into quality improvement efforts is increasingly prioritised in healthcare services (Garratt, 2008). A set of rules and regulations governs implementation of EBM and patient-centred principles (e.g. Ferlie and McGivern, 2014), and form part of the management and evaluation systems that can exert pressure on healthcare professionals (Numerato et al., 2012).

 Healthcare professionals are asked to try to understand what it is like to live with a health condition and to incorporate patient experiences into their routine work. Care should be compassionate (Institute of Medicine, 2001; Department of Health, 2008) with healthcare professionals engaging with emotional and contextual aspects of the illness experience in their work to improve service quality (henceforth: quality improvement) (e.g. Martin, 2012; Komporozos-Athanasiou and Thompson, 2015).

EBM has been criticised for privileging 'decontextualised' (Moreira, 2012: 308) and 'disembodied' (Wood et al., 1998: 1730) forms of knowledge (see also Goldenberg, 2006). EBM is often articulated in terms of and underpinned by ideas about hierarchies of evidence (Lambert, 2006), where 'rational/technical' evidence ranks above 'contingent/experiential' evidence (Pope, 2003: 269). Within a patient-centred approach to care, on the other hand, engaging with patients' experience narratives is vital because these constitute 'phenomenal' forms of evidence (Schellenberg, 2013: 487) conveying somatic, emotional and social aspects of illness.

We conceptualise knowledge as both a process and a resource for sense-making and action (Jovchelovitch, 2007). As a dialogic process (Marková, 2000, 2003; Jovchelovitch, 2007; Tsoukas, 2009; Renedo, 2010), professional knowledge is shaped by multiple, often heterogeneous beliefs, values and 'rationalities' (May et al., 2006). This view of knowledge emphasises the social nature of knowledge production – that is, that knowledge is produced through and against relationships with multiple others and through participation in diverse sociocultural contexts (Jovchelovitch, 2007). Different 'rationalities' may co-exist side by side within the same person (Wagner et al., 2000; Provencher, 2011) or group of people (Jovchelovitch, 2007; Gervais and Jovchelovitch, 1998; Moscovici, 1874/2008), influencing each other (Mouro and Castro, 2012) and potentially producing new forms of hybrid knowledge. Involving and working with patients in healthcare improvement and health research provides one of many dialogues in which a professional's knowledge is articulated and developed. Dialogues between professionals and other stakeholders such as managers, policy makers and commissioners provide additional materials and epistemes such as policies, institutional discourses, biomedical evidence, through which professional knowledge is also produced.

Social and institutional contexts (May, 2007; Egan and Jaye, 2009) affect the hybrid knowledge(s) produced. Healthcare professionals navigate between multiple epistemes; from scientific 'facts' and

clinical guidelines, to their own personal experience and institutional discourses (e.g. EBM, patient-centred care). Some questions arise from this: How do healthcare professionals establish dialogue between repertoire of epistemes available to them, and how do they incorporate patient experience? How do they appropriate and incorporate patient experiences into processes of knowledge production while also responding to an evidence-based medicine framework? We propose that a dialogic conceptual frame helps address these questions.

Hybrid knowledge and dialogue

Knowledge is characterised by hybridity, that is, the combination of what at first might appear to be incompatible epistemes (Moscovici and Marková, 2000; Jovchelovitch, 2002). People use multiple, and at times conflicting, forms of thinking, logics and explanations derived from their socio-cultural and institutional contexts, to make sense of and organise their experience around the same object of knowledge (Wagner et al., 2000; Renedo, 2010). Hybridity applies both to lay people and experts (Jovchelovitch and Priego-Hernandez, 2015). The idea that knowledge is hybrid can help explain how biomedical knowledge does not have demarcated boundaries and is not exclusive to a particular group (doctors, scientists) or social sphere (laboratory, clinical practice). Biomedical knowledge travels to other spaces, permeates, influences and is influenced by other types of knowledge. Patients for example draw on a mix of illness experiential and biomedical epistemes (Pols, 2014), religious and cultural values, and 'common sense' to conceptualise their illness experiences (de-Graft Aikins, 2003; Jovchelovitch and Gervais, 1999). Patients can also transform how 'biomedical knowledge gets made' (Epstein, 1996: 336). Experts may use competing therapeutic models and caring approaches, blending them with policy discourses and institutional demands to make sense of and address the object of their work (e.g. mental health Morant, 2006; homelessness Renedo and Jovchelovitch, 2007).

In order to examine how hybrid knowledge (Jovchelovitch, 2007; Keshet, 2010) is created we draw on Bakhtin's ideas about dialogue (Bakhtin, 1981, 1984, 1986). This approach helps us understand how people shape the knowledge that they develop *through* their engagement in dialogue with multiple beliefs, values and 'rationalities' that circulate around them (Jovchelovitch, 2002). Knowledge is produced through and against a 'polyphony' (Bakhtin, 1984) of others' voices and the forms of knowledge (i.e. epistemes) these voices convey (Renedo, 2010), creating dialogical tensions (Marková, 2003; Renedo, 2010) and contradiction between interacting or contradictory epistemes. The hybridity of knowledge is a product of the dialogical nature of human beings and social life. People exist in external and internal dialogue with a polyphony of others' voices and epistemes (imagined or 'real'), including others they encountered in the past, and those they relate to in the present (e.g. my partner, my institution, my community) (Bakhtin, 1984, 1986). This dialogicality involves an ability to address and respond to others, and position oneself in relation to their voices and epistemes (Bakhtin, 1986).

This Bakhtinian notion of dialogism helps us conceptualise the relational and contextually-situated nature of professional knowledge in two major ways.

First, dialogical 'appropriation' (Bakhtin, 1981) helps us understand how hybrid forms of knowledge may be produced through dialogue with a polyphony of others and through re-working of others' epistemes. By 'appropriation', Bakhtin (1981) refers to the process of actively re-negotiating and re-working others' perspectives (i.e. epistemes), investing them with one's own 'accents' (Bakhtin,

1981). One creates new forms of knowledge by 're-accentuating' (Bakhtin, 1981) others' epistemes (infusing them with one's own values and intentions). These new forms of knowledge are hybrid because they contain traces of the polyphony of others' epistemes, although they now have different accents (i.e. re-interpretations). It is this process of dialogue and appropriation that makes the knowledge an individual holds hybrid.

Second, it helps us examine how knowledge is unfinalized, fluid, and open to re-articulation through dialogue. New types of social interactions and social engagements may contribute to this ongoing production. Through appropriation, some perspectives are expanded and re-accentuated, while others may be silenced or excluded (Jovchelovitch, 2007). Conflict, contradiction and 'forces of coercion' are inherent to dialogue (Gurevitch, 2000: 243). The outcome of the dialogical process then, depends on how different epistemes communicate with each other, and on whether they are asymmetrical with respect to the legitimacy granted to each of them (e.g. scientific epistemes may be considered superior to lay or common-sense epistemes or versus managerial/institutional epistemes) (Jovchelovitch, 2007). Bakhtin's concepts have proved useful beyond the field of literary theory, informing social theory and analysis of the intersubjective nature of society, sense-making and identity (e.g. multivoiced Self (Aveling et al., 2015), dialogical self (Hermans, 2001)).

Methods

In this paper we draw on data from 29 in-depth 60-120-minute individual interviews and a 90 min group interview (N=4) with healthcare professionals (clinicians /clinical and healthcare researchers whose work focused on various chronic conditions, such as different types of cancer and respiratory diseases)[1] who are required to involve patients in their healthcare improvement and research activities. Interviews were conducted as part of two larger ethnographic projects exploring the patient and public involvement activities of a UK clinical research network and a healthcare services quality improvement initiative in London (Collaborations for Leadership in Applied Health Research and Care, CLAHRC NWL). As part of one these ethnographic projects we conducted planned observation of official patient and public involvement activities: over 100 hours at the clinical research network and 132 hours at CLAHRC NWL. These included meetings of healthcare professionals and patients working together on projects to try to improve particular healthcare services, and on the development and prioritisation of new health research, including deliberative exercises about strategic priorities, design, and implementation.

All interviews were audio-recorded and transcribed verbatim. Interviews covered healthcare professionals' understandings and experiences of involving patients, as well their views on patients' role in healthcare improvement and research. Through observation we examined how healthcare professionals interacted with patients involved in healthcare improvement and research activities. We focused on practical (Emerson et al., 1995), emotional (e.g. how people draw on lived experience to contribute to professional-patient discussions), and contextual/spatial aspects (Renedo and Marston, 2015b) of participation (e.g. how people use space, what practices they develop). We report additional findings elsewhere (Renedo and Marston, 2015b; Komporozos-Athanasiou and Thompson, 2015; Komporozos-Athanasiou et al., 2016).

We do not follow a 'pure' Bakhtinian approach to analysing language. Our analysis is dialogic in that its focus goes beyond immediate speech/text as abstract reified forms (e.g. morphemes, sentences,

syntactical structure) independent from the outside world, recognising instead the contextuality of language and of the dialogues refracted through interview talk (Marková, 2003; Linell, 2009). Our approach is influenced by others who have used Bahktin's work outside literary theory (e.g. Aveling et al., 2015; Hermans, 2001).

We analysed one-to-one and group interviews using a combined iterative thematic and dialogical approach focused on two interrelated dimensions: content and processes. Our coding frame was developed inductively from the entire data set (Charmaz, 2006). This process was informed by our a priori interest in the dialogical nature of knowledge and was guided by Bakhtin's view that meaning is constructed and conveyed through dialogue with the polyphony of others – a process that involves the interlocutor addressing, responding to, appropriating and re-constructing others' voices and world views (Bakhtin, 1984). We used iterative thematic analysis (Attride-Stirling, 2001) to identify the key meanings and symbols through which professionals articulated their views on patient experience and patient participation in healthcare. Informed by Bakhtin's ideas about 'polyphony' (Bakhtin, 1984), 'addressivity' (Bakhtin, 1986) and dialogical 'appropriation' (Bakhtin, 1981) we focused on how these meanings and symbols were articulated in a dialogic manner, that is, through different voices addressing and responding to each other. We conducted an analysis of dialogues expressed in healthcare professionals' narratives (Aveling et al., 2015; Renedo, 2010) to examine how the themes were interconnected and to identify the dynamics of the contents within each theme. This analysis of dialogues focused on the dialectical relationship between responsive and interconnected utterances (i.e. how an utterance qualified a preceding one by, for instance, denying it, reaffirming it, or investing it with new meaning (Bakhtin, 1986)). We examined utterances in the context of the whole interview and in relation to the wider context of the research (Aveling et al., 2015). For this 'text-in-context' analysis we drew on the contextual knowledge gained through our ethnographies, as well as other sources such as relevant sociological and public health literature. This allowed us to transcend immediate text/speech utterances. Through close attention to the interview context and wider research context of utterances the possible social origin of voices expressed in interviewees' utterances became clearer (Aveling et al., 2015). This iterative dialogical analysis allowed us to examine relationships between multiple voices as they appear within interviewees' talk and the ways in which knowledge content was constructed and negotiated through dialogue these voices. During repeated rounds of coding, re-coding, and 'memo-writing' (Charmaz, 2006) about themes and about their dialogical production (about voices present in the narratives, the social origin of languages echoed, dynamics between voices (Aveling et al., 2015)), we made frequent comparisons across the interview data, to generate and refine analytical categories.

We presented ourselves to participants as independent academics, and outsiders to their healthcare institutions. We explained that we were not 'evaluating' their patient involvement practices. However, our position as researchers of an initiative that recognises the need to incorporate patient experience into healthcare services could still make participants assume we aligned ourselves with such initiative, which could in turn foreground particular dialogical dynamics and patient voices. In the analysis we attended to our role as researchers in the co-production of interview data (how interviewees were engaging in dialogue with us, addressing us and responding to what they might have anticipated our views were). We also examined the data reflexively as a dialogue between 'us' as researchers and the transcript as an interlocutor in the analysis process. The first and second

authors had conducted interviews and so were 'closer' to the data than the third author who had not. Our analysis itself was also the product of the dialogues between the authors.

Findings

Our interviews and observations reveal tensions in the way healthcare professionals (interviewees) related to patients participating in research and healthcare services (patient participants). Two major themes emerged in the dialogues we analysed: 'instrumentalising experiences' and 'de-subjectifying experiences'. We examine in detail interview quotations that illustrate the complexity and nuance within these dialogues, while also representing the plurality of voices through which these themes emerged.

Instrumentalising experience

Professionals' accounts highlighted the added value of patients' narratives about patients' unique embodied experiences of illness and of healthcare services (Quote 1). Echoing discourses about patient-centredness, interviewees often talked about the value of involving patients, referring to how patients' contributions were grounded in 'real' experiences and providing this as a justification for patient involvement. Using second person pronouns ('you've got [...] you haven't got [...] helps you' (Quote 1)) they seemingly addressed their social group (healthcare professionals, researchers) asserting the need for them to engage with patients' lived experiences (Quote 3). Yet there was a clear shift in their narratives to a different and more dominant position marked by the use of deontic language conveying obligation ('I thought she should be [useful]' Quote 2) and first person plural ('[patients] giving us [ideas, information]' Quote 1, Quote 3, 'we have to balance [patient experience]' Quote 5, 'we can use' Quote 4) which suggested they took a broadly instrumental attitude to involving patients and to engaging with patient experiences (Quote 2). This more dominant voice in their narratives echoed the language typical of evidence-based medicine (EBM) (Quote 3).

> *[quality improvement without patient involvement] it's like a jigsaw and you've got a missing piece, you haven't got the whole picture [...] [patient involvement] it is giving us a broader view of what people think, it is helping us to evolve some decisions [...] what it helps you to do is to shape something that I think is a bit more grounded in people's real experiences.*

Quote 1, (Interviewee E, Quality improvement manager)

> *Whilst I would say I've learnt a lot about PPI [patient and public involvement] and I'm quite a convert and I think, it's, it's an incredibly, it could, it can be incredibly valuable, and it could be a useful tool that researchers can exploit for themselves to generate the richest sort of research questions and generate protocols that are most likely to be acceptable and generate good data [...]she [patient] wasn't as useful as I thought she would be in the early stage but latterly she has been.*

Quote 2 (Interviewee B, Clinician)

When describing their interactions with patients (as part of their involvement activities) interviewees talked about patients in terms of how their healthcare experience narratives were useful for achieving specific goals of knowledge production. Professionals talked about using such narratives to expand their knowledge base about healthcare conditions or to validate their own existing ideas about how to improve services. In doing so interviewees re-formulated and 're-accentuated'

([Bakhtin, 1981](#)) the 'lived experience' discourse with intentions typical of EBM (emphasis on knowledge production and incorporation of evidence into everyday work), with patient experience narratives becoming commodities that add to or validate professionals' own knowledge (Quote 1, Quote 2). The lived experience discourse, then, was focused on the epistemological potential of patients' subjective experience, and on the knowledge and perspectives patients develop through illness and healthcare experiences, along with the potential for these to be turned into data. Lived experience was anchored within an EBM framework with interviewees investing experience with 'accents' ([Bakhtin, 1981](#)) typical of the scientific method as illustrated in the use of terms such as 'test' (Quote 3). This layering of different voices reflected discourses of 'science', EBM and patient-centred care, and was played out in a hybrid construction of experience as 'lived evidence base' (Quote 3).

> *Without the patients in all these projects, there is really no sort of evidence base is there? So there is no real evidence base or lived evidence base, it is, […], research taken from here, here and there, and you have really got to test it within the likely environment […] people are giving us information and really sort of rich information and evidence.*

Quote 3 (Interviewee C, Quality improvement manager)

Experience was reified into something that exists 'out there' independent from the living and feeling person, and that can be unproblematically extracted, collected and commodified (Quote 2, Quote 4). The instrumental approach to patients' subjective experiences was manifest in the way interviewees frequently talked about patient 'views' and patient 'perspectives' as forms of 'evidence' (Quote 3) and 'reality checks', for instance by focusing on patients' cognition and on the patient as a thinking subject. As interviewee B (Quote 2) put it, patients can be 'exploit[ed]' to generate knowledge and 'data'.

> *It [patient and public involvement] means […] giving us ideas of how best to […] use patients' feedback to improve your service improvement project. [...] It may not always be the right thing but, […] we need to look at the whole picture and get as many comments from patients as possible to see how we can use this […] I think we've achieved quite a lot of, with their [patients'] input. […] I consider myself very lucky with my two patients.*

Quote 4 (Interviewee A, Clinician)

In seeking to develop evidence and knowledge (Quote 1, Quote 3, Quote 6) about patient experience professionals seemed to be invoking the voice of biomedical science to position themselves both within the relationship with patients and within their institutional context with its particular demands (Quote 5), seeming to infuse patient experience narratives with normative scientific 'accents' ([Bakhtin, 1981](#)) (e.g. Quote 5 'recall bias', representativeness). Professionals re-articulated the narratives as amenable to external use and judgment, for instance by establishing the degree to which those experiences are 'useful'. In Quote 4, interviewee A initially adopts scientific 'evaluative accents' ([Voloshinov, 1986](#)), saying that using patient experience feedback is not always 'the right thing', while later on he talks about its value. The shift may reflect the fact that the interviewer researches patient involvement. Professionals referred to accessing patient voices as ways of imparting 'validity' to the work they do. Failing to involve patients leaves professionals with a 'missing piece' in the 'jigsaw' without the 'whole picture' (Quote 1).

> *It's really important to feed that [experience of living with cancer] into a process but we*
> *have to balance that with (a) recall bias, (b) the fact that these individuals are usually one or*
> *two voices on a very disease-orientated committee and see the fact that actually they're not*
> *representing anybody other than themselves because they can't, because they've not got*
> *that collective viewpoint. […]*

Quote 5 (Interviewee G, Clinical researcher)

The use of 'but' in Quote 5 (it's important… but) marks a shift in interviewee G's narrative towards an instrumental approach and suggests a 'dialogical knot' or tension (Aveling et al., 2015: 13) between discourses about patient-centredness and the more dominant voices of biomedical science and EBM. It is from this more authoritative, latter voice that interviewee G asserts patients' inability to represent others; a 'fact' that is reinforced by the use of 'actually' followed by a list of 'facts' about patients' shortcomings. Interviewees often mentioned 'using' patients for their quality improvement tasks (e.g. receiving experience-based feedback), referred to patients in possessive terms ('my two patients') (Quote 4), and talked about how 'useful' their patients' contributions were (Quote 2). Interviewees wanted patient presence in their teams (often referring to involvement as 'recruitment') but did not usually talk about the quality of relationships with patients or the process of building these relationships. Interviewees neither elaborated on emotional aspects of involving patients, nor used emotive language.

De-subjectifying experiences

Interviewees said they valued experience narratives (perhaps because they were talking to us) but also seemed to require that those narratives be abstracted from the patients' biographies and bodies (Quote 5, Quote 6) with some explicitly mentioning the need to remove emotional aspects of lived experience, 'look beyond emotion' as Interviewee N put it.

> *[…] quite often you don't really want the user to talk just about their own experience. <u>And</u>*
> *that's very interesting and helpful <u>but</u> what you really want them to do is think about how it*
> *affects people in general […] when they do think about it altruistically from other's point of*
> *view, as a lay person, that is the point of view that I find very helpful. [...] There should be*
> *training in terms of trying to put themselves in other people's shoes. So what would be really*
> *helpful is if a user was able to think, 'Well how might this impact on someone who has*
> *severely difficult social circumstances, or difficult … or was illiterate, for example.' So you*
> *want them to just be able to perceive the world quite broadly.*

Quote 6 (Interviewee F, Clinical researcher) Our emphasis.

Taking others' positions and talking from others' perspectives becomes a task for patients (rather than professionals) and requires their personal improvement through 'training'. Interviewee F (Quote 6) appeals to patients ('you want them to… perceive the world… broadly'), asking them to have some kind of embodied 'broad' experience of others ('how it affects people in general'). F's use of 'and' and 'but' in the second sentence suggests some doubt about whether or not to value personal experiences, which he seems to resolve by suggesting patients should step out of themselves somehow, in order that their participation might happen in disembodied ways. F equates the ability to decentre and take another's perspective with 'altruism', implying that it might be selfish to take only one's own experience into account. To make the point, F switches to a different voice, seemingly that of the idealised altruistic patient (as marked by the use of direct

quotations) perhaps to try to indicate that this is indeed possible or attempting to exemplify the reflexivity involved in de-subjectifying patient experience.

Professionals talking about the validity of patient narratives used vocabulary (generalisability and representativeness) typical of the biomedical scientific paradigm (e.g. patients speaking from a 'general lay perspective' (Quote 9)). It appears that although patients were invited to participate because of their phenomenological experience, they were simultaneously asked to contribute disembodied accounts that conform to specific expectations, and ultimately to de-centre themselves from their core experience. F even suggests they be trained to do this (Quote 6). This process of distilling patient voices from subjective noise (silencing the patient experience) seemed important in professionals' attempts to separate evidence from non-evidence.

Interviewees saw more value in patient experience narratives that were detached from the embodied experience of the person and were instead able to convey the experiences of a generalized patient other – often described as the 'average' patient (Quote 6, Quote 7). This placed contradictory demands on patients who in effect were expected to contribute subjective illness experiences in order to be 'useful' to professionals, but whose own subjectivity was devalued as a form of evidence. During fieldwork we saw professionals actively recruiting patients who did not simply speak or act from a single personal voice and experience and who they characterised using favourable terms ('articulate', 'intelligent').

> *The only time that I've ever come… encountered anyone who was able to step outside of their own perspective from PPI was a woman [...] [she] was excellent. […] she was fairly intelligent to start off with. […] she had a pre-existing set of skills which were helpful for exactly the task which she was being asked to do. [...] she had some training, and so she was actually able to look at it from a kind of complex lay perspective [...] [a perspective] that's broader and more general.*

Quote 7 (Interviewee I, Clinician)

Professionals favouring 'de-centered' or 'disembodied' participation may limit what patients can say or do to be perceived as legitimate or useful participant narrators of the illness experience. This was also manifest in the nature of the 'participatory spaces' (Renedo and Marston, 2015b) that professionals created to solicit patients' opinions. Interactions often consisted of sitting 'around the table' (Stern and Green, 2008) in committees and board meetings. Experience narratives in these officialised spaces were restricted by practices that prioritised reason/cognition over emotion (Komporozos-Athanasiou and Thompson, 2015) and consisted of formal conventions such as meeting agendas and minutes to record participants' input and use of technical language that discouraged first-person accounts and expressions of experiential forms of knowledge (Renedo and Marston, 2015b). Healthcare professionals drafted role descriptions for patients to ensure patients contributed effectively and knew what professionals wanted from their participation.

> *How can you get […] a more structured or routine way to collect patient experience around well actually what does work and what doesn't work? [...]they [patients] have a role to play, but obviously that's balanced with a lot of other kind of information, or evidence.*

Quote 8 (Focus group participant, Quality improvement manager)

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> *What you want is someone who can step outside of their own perspective to give you a general lay perspective [...] you do need to be able to see outside of your own narrow experience [...] actually you want a series of people's perspectives on it, and even then you have to be extremely careful [...] about how you do it. You then also have to temper the patient experience with what's pragmatic [...] The question is, how you access it. Do you need a focus group, do you need a single patient? What sort of training does the patient need?*

Quote 9 (Interviewee K, Clinician)

While interviewees orientated their utterances to patients as potentially active participants in evidence-making about patient experience through their disembodied accounts ('step outside of their own perspective' Quote 9), at points they shifted to a rather more authoritative position (as illustrated by the use of obligative/deontic language seemingly orientated towards an absent patient ('you do need to be able to …') or by excluding patients from this process ('you [professional] have to temper' Quote 9). K (Quote 9) says patients should 'see outside of [their] own narrow experience' but then explains how 'you' (seemingly meaning the healthcare professional) 'even then' must be 'careful' of how this is done, i.e. that professionals need to manage the process. Interviewees' accounts reveal their concern that patients are unable to step out of their realm of personal experience to develop knowledge that is representative of the experiences of a 'standard' or generalized/generalizable patient (Quote 7, Quote 5, Quote 8).

Narratives were permeated by 'evaluative accents' (Voloshinov, 1986) about patient experience (e.g. 'narrow' Quote 9) and about patients' ability to articulate experience as evidence (references to 'training', the use of words such as 'can', 'able to' (Quote 6, Quote 7 ,Quote 9)). Interviewees also talked about finding mechanisms to manage and manipulate patient narratives to remove subjective elements - e.g. 'structured or routine' ways to collect (Quote 9) 'temper[ing]' patient experience (Quote 9), 'balanc[ing]' patients with other types of evidence (Quote 8). Here interviewees positioned themselves as regulators of lived experience as evidence and drew on the authoritative voice associated with medical and clinical research expertise. Concern with finding a reliable method to learn about the 'universals' of patient experience was common. Interviewees often referred to the need to apply some 'rigour' and 'structure' to the way they collected patient narratives. Patient experience was positioned as something imperfect in itself that professionals can nevertheless appropriate and manipulate to develop knowledge about the universals of patient experience.

In rare cases, interviewees used metaphors that emphasized patients' humanity. For instance, mentioning the importance of transitioning towards a relationship between the professional and patient, and the value of gaining a sense of the person and of his or her lived experience. These professionals accounts nevertheless also retained language suggesting instrumentality and commodification of patients' experience narratives which co-existed in tension with the more relational and existential language about patient involvement.

> *Having the two chaps with [chronic condition] and their personal experience […] make it real and make it come to life. And reminds us all why we're doing it […] because we're not dealing with hypothetical patients. We're dealing with people that have, are living and breathing. […] Well, it is that reminder […] that it's a very real situation. It, it sort of spurs you on a little bit to, to deliver what, what we should be delivering.*

Quote 10 (Interviewee M, Quality improvement manager)

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Interviewee M describes becoming sensitively attuned to patients' life conditions (Quote 10). She reflects about how being open to the presence of the 'living and breathing patient' has an impact on herself as a person.

Discussion

In this paper we have shown how hybrid knowledge is developed in dialogue with a range of voices and associated epistemes circulating in healthcare professionals' work environments pertaining, for instance, to EBM, biomedical science, and patient-centredness. Through this dialogical process patient experiences are re-articulated with 'intentions' and 'accents' ([Bakhtin, 1981](#)) reflecting the diverse epistemes and demands of healthcare services. Scientific knowledge is often conceptualized within healthcare as unproblematic, held by and for clinicians and other healthcare professionals to improve patient lives. Understanding knowledge as relational and hybrid helps us move beyond assumptions about a dichotomy between 'objective science' and 'subjective experience'. Our Bakhtinian approach helps understand how a dialogical process involving healthcare providers and patient participants may result in amalgamation, appropriation and accenting of epistemes, in a process of hybrid knowledge production. This process may translate into contradictory ways of relating to and involving patients.

Our analysis illustrates how dialogical processes lead to new knowledge emerging when professionals engage with "lay" patient knowledge, and helps inform the sociology of knowledge production more widely.

First, our analysis suggests that the fluid and unfinalized nature of knowledge production means new forms of engaging with and incorporating patient experience may emerge. These, as we explain below, harbour the potential for more meaningful participation, but also present risks for the relationship between professionals and patients that if unaddressed may undermine participation initiatives. Healthcare professionals expressed ideas about enlightenment through patient experience narratives, which recall Cartesian epistemological goals to discover universals and truths, in this case about patient experience. They turned to the patient and positioned themselves in relation to his or her experiences to generate evidence and improve knowledge, for instance to inform research questions and protocols. Professionals appeared to welcome patients' personal experiences of illness when they, the professionals, perceived them to be useful. Nevertheless, their narratives suggested that they simultaneously devalued patients' subjective, private experiences as sources of evidence, and asked patients to transcend the same illness and healthcare experiences that had led them to participate in the first place.

Such emphasis on de-contextualisation from personal embodied experiences could strain the patient-professional relationship. Patients are simultaneously asked to be nobody (by silencing their personal lived experiences and putting aside their own idiosyncrasies) and everybody (by having embodied broad experiences or views that are representative of others). Demanding that patients de-centre their experience narratives from the uniqueness of the self, identifying with others and contributing from these others' perspectives seems objectifying in not only 'denying […] the[ir] status of beings ends in themselves' [sic] ([Nussbaum, 1995: 265](#)) but also treating them as 'fungible' ([Nussbaum, 1995: 260](#)) i.e. 'interchangeable with others of the same type' ([Nussbaum, 1995: 257](#)). These contradictory demands on patients reflected in professionals' knowledge also echo neoliberal

imperatives for patient self-governance and for the production of a particular type of patient participant able to self-regulate personal experiences (Renedo and Marston, 2015a). Such demands on patients also point to the obstacles professionals face in developing relationships with patients that would enable professionals to connect to the uniqueness of illness experiences. Ultimately, these tensions may jeopardise the clinician-patient relationship.

The second contribution of this paper is showing how the tensions and contradictory demands placed on patients mirror the institutional challenges that professionals face in articulating and amalgamating different and competing values: the need to integrate patient-centred and evidence-based agendas, the difficulties of establishing dialogue between biomedical and experiential (situated) knowledge systems, the intricacies of reconciling private (personal/ affective) and public (collective/rational) realms of life, and the increasing requirement to collect, quantify and incorporate patient experience data. In this context, the development of hybrid knowledge may have an adaptive function (Jovchelovitch, 2007), helping professionals position themselves appropriately in their workplace.

Relating to patient experience appears not to be simply about patient-centred improvements in care, and recognising the epistemic value of experience. It is also adaptive for healthcare professionals in that it turns patient experiences into epistemic commodities useful – or perceived as useful – in the contemporary healthcare context, distilling abstract or general experience from subjective noise, adopting means-orientated instrumental relations with patients, privileging disembodied forms of patient involvement, and assessing the evidentiary status of patient voices. The dominance of certain institutional voices and their epistemes (associated with EBM and rational/clinical research) makes the process of engaging with patient experience far from straightforward, yet as we have shown, professionals can also adopt existential and relational counter-positions. Their accounts suggest that they attempt to interweave different epistemes (e.g. knowledge based on lived /embodied illness experiences and scientific biomedical knowledge) and resolve tensions between them. Professionals appropriated, and 're-accentuated' (Bakhtin, 1981) rational scientific institutional discourses using existential/relational discourses derived from their own experiences of relating to patients, and in doing so they re-worked and brought new meanings to patient experience. In these instances, patient experience was reconstructed as immediate and real to these healthcare professionals, who for instance recognised becoming sensitively connected with patient experiences.

Our own position as researchers with an interest in patient involvement might have set up a particular dynamic in this study, which could have encouraged interviewees to add positive notes to their narratives of patient experiences. Regardless, it seems likely that in producing knowledge from dialogue, some voices and perspectives have greater authority than others. In the case of our interviewees, perspectives associated with EBM and biomedical science had more weight and in the dialogue these perspectives 'accented' talk about patient experiential voices and discourses about patient-centredness. New counter-positions may also emerge that re-negotiate and transform knowledge – as in those rare cases in which professionals emphasised the importance of gaining a sense of patients' lived experience and the need to develop alternative ways of relating to them.

Knowledge may stagnate if monological healthcare practices – that is, excluding or subordinating patient experiential voices to others' more 'valid' voices and epistemes – are prioritised over

encounters with transformative potential. In 'transformative encounters' (Aveling and Jovchelovitch, 2013) partners engage with each other's perspective without imposing their own as a more legitimate form of knowledge. In these encounters, dialogical tensions between different types of knowledge can become productive by giving way to novel, co-produced knowledge: these are hybridisations in which epistemes may amalgamate more evenly (Aveling and Jovchelovitch, 2013). Our study, however, suggests that developing transformative encounters may prove challenging for those working in increasingly 'managerial cultures' (Numerato et al., 2012: 630) characterized by insistence on metrics and pressures to reduce costs while increasing productivity; institutional environments that may not easily accommodate personal experiences, and are likely to foster rather than address hierarchical differentials between epistemes. Tensions are inherent in hybrid knowledge produced in these environments and reflect the negotiated nature of healthcare, including the 'vulnerabilities, difficulties and threats of the [dialogical] encounter' (Gurevitch, 2000: 250) between patients and professionals. Rather than simply encouraging experience to be used as an epistemic commodity, institutional environments should facilitate transformative encounters and help individuals engage with experience as part of a relational process. Creating enabling environments is important if we are to allow new forms of knowledge – and improvements in patient care that might result – to emerge from the burgeoning patient participation initiatives within healthcare services.

Acknowledgement

Disclaimer

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[1] To preserve anonymity, we have omitted further details about the clinical roles, clinical context and research field of participants.

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Biographies

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