

Research Bank

Journal article

Knowledge matters : Producing and using knowledge to navigate healthcare systems

Willis, Karen, Collyer, Fran, Lewis, Sophie, Gabe, Jonathan, Flaherty, Ian and Calnan, Michael

This is an Accepted Manuscript version of the following article, accepted for publication in *Health Sociology Review*.

Willis, K., Collyer, F., Lewis, S., Gabe, J., Flaherty, I. and Calnan, M. (2016). Knowledge matters: Producing and using knowledge to navigate healthcare systems. *Health Sociology Review*, 25(2), pp. 202-216. https://doi.org/10.1080/14461242.2016.1170624.

It is deposited under the terms of the <u>Creative Commons Attribution-NonCommercial-NoDerivatives License</u>, which permits non-commercial re-use, distribution, and reproduction in any medium, provided the original work is properly cited, and is not altered, transformed, or built upon in any way.

Knowledge Matters: Producing and using knowledge to navigate healthcare systems

Professor Karen Willis, Faculty of Health Sciences, Australian Catholic University, Melbourne, Victoria, Australia. <u>Karen.willis@acu.edu.au</u>

Associate Professor Fran Collyer, Department of Sociology and Social Policy, The University of Sydney, Sydney, New South Wales, Australia. Fran.Collyer@sydney.edu.au

Dr Sophie Lewis, Faculty of Health Sciences, The University of Sydney, Sydney, New South Wales, Australia. Sophie.Lewis@sydney.edu.au

Professor Jonathon Gabe, Royal Holloway, The University of London, London, United Kingdom. lgabe@rhul.ac.uk

Ian Flaherty, Department of Sociology and Social Policy, The University of Sydney, Sydney, New South Wales, Australia. Ian.Flaherty@sydney.edu.au

Professor Michael Calnan, School of Social Policy, Sociology and Social Research, the University of Kent, Kent, United Kingdom. <u>M.w.calnan@kent.ac.uk</u>

Published in *Health Sociology Review*, 2016, 25, 2 http://dx.doi.org/10.1080/14461242.2016.1170624

Abstract

In many contemporary healthcare systems, individuals are expected to be rational actors – weighing up available knowledge and making choices about their healthcare needs. In the policy context this has been most explicitly applied to the financing of healthcare where there is encouragement for the purchase of private health insurance. However, perceptions of public and private healthcare provision, knowledge about healthcare needs, and the types of services people choose, are far from straightforward. Drawing on Bourdieu's concepts of habitus, field and capital, and a study of individual experiences of choice in Australian healthcare, we explore the knowledges used by people as they navigate through the healthcare system. Such navigation takes place in a milieu where authoritative medical knowledge intersects with knowledge from other sources, including the Internet and lived experience. However, our study reveals that navigation of healthcare is assisted most of all by the capacity to draw on 'system knowledge'. System knowledge takes two, sometimes overlapping, forms. First, acquired system knowledge is produced through drawing on experience, formal knowledge and the capacity to undertake research (primarily cultural capital). Second, assumed system knowledge enables navigation of the healthcare system through accessing and utilising networks of privilege (primarily economic and social capital).

Keywords: choice; healthcare knowledge; health system; Bourdieu

Introduction

In recent years the discourse of 'patient choice' has grown in popularity in several of the world's healthcare systems, particularly in countries such as Australia, the United Kingdom and Sweden, where governments have actively encouraged the expansion of a private healthcare industry amidst the network of publicly owned and managed healthcare services. The discourse of choice has, in these countries, been taken up by neo-liberal governments as the solution to system failure problems, and indeed become an imperative for all citizens. Citizens are urged to take individual responsibility for their health and become 'expert patients' (Taylor and Bury 2007). These developments have taken place in concert with a proliferation of knowledge about health matters, particularly from the news media and the Internet (Hesse et al, 2005). These various sources of knowledge offer new sites for contestations over healthcare knowledge (Hardey, 1999), but have nevertheless become increasingly common and 'unremarkable' (Chapple, Evans and Ziebland, 2012). For example, when people make healthcare decisions, they use the Internet to find information and support not provided through more orthodox healthcare channels about such matters as second opinions or alternative treatments, the experiences of others, the backgrounds of treating doctors and the interpretation of diagnosis (Ziebland et al, 2004). Some research suggests that the healthcare information gleaned from the Internet can improve the decision-making process (Gerber and Eiser, 2001). For example, in the face of serious illness, patients may use knowledge acquired through the Internet to 'display competence' (Ziebland et al, 2004) not only in becoming familiar with technical or medical terms, but also meeting the changing definitions of being a 'good patient'.

The increasing range of information about healthcare, and the imperative to gain knowledge about, and choose between, an array of services and treatments is an area that requires the close attention of researchers. In focusing on the notion of healthcare knowledge, it becomes immediately apparent that there are a number of problems with the idea of the knowledgeable, expert patient. To begin, examination of prevailing discourses about 'choice' in healthcare and the accompanying policy context, reveals that the notion of choice is based on a view of decision-making as a process of cost benefit assessment. Such discourses and policies take a rational choice approach to human behaviour and do not accord well with sociological understandings of social action (Collyer et al, 2015; Greener, 2003). Three assumptions about human behaviour are well captured within rational choice theory. First, this theory of human behaviour presumes choice to be an inherent good, with humans desirous and capable of managing unlimited choice (Iyengar and Lepper, 2000); second, people always act rationally and with intention; and third, a given individual will repeat the same choices, regardless of their social circumstances and context (Levin and Milgrom, 2004). This perspective also resonates with contemporary societal values, such that it "is much more than a working hypothesis; it is an article of faith grounded in a deep commitment to the value of liberty" (Etzioni in Pescosolido, 1992, p.1101). The sociological literature however, proffers a wealth

of evidence to counter this view. Individual experiences are shown to be limited and constrained by the operation of various social structures, and choices in the healthcare field are rarely based on rational calculation but guided and managed in the interactive context. Thus, in situations where they are at their most vulnerable, individuals rely heavily on the generally greater medical knowledge of their healthcare practitioners, their own experiences and experiences of their friends and family (Dixon et al, 2010; Frank and Zeckhauser, 2009). Such studies make the neoliberal assumption of the rational and informed healthcare consumer incongruous (Harley et al, 2011; Greener, 2003).

The management and control of patient choices and practices through cultural and institutional means has been a mainstay of health sociology since Talcott Parsons' investigations into the 'sick role' (Willis, 2015; Armstrong, 2013). Sociologists have demonstrated that individual choices and experiences are partly the consequence of the knowledge they bring to their interactions with healthcare practitioners, but these interactions are themselves structured and constrained by widespread public discourses about healthcare, as well as by the organisation of the healthcare setting itself, for instance by its payment systems (Shim, 2010). Further, the pressure on individuals to take an active role in the healthcare system, the popularity of the discourse of choice as a mantra of government, and the government's growing investment in the private healthcare industry, are not coincidental developments. Elsewhere (Collyer et al, 2015) we have argued that policies to encourage 'greater choice' do not seek to offer a broad range of alternatives, but are strategies aimed at enouraging citizens into 'going private'.

These sociological studies suggest a need to problematise the concept of knowledge itself, and ask questions about the kinds of knowledge patients have at their disposal, and how they might utilise these in the healthcare setting. Sociological studies have proposed various types of health-related knowledge, all of which might be applied in healthcare, including scientific/medical, expert knowledge, lay knowledge, and experiential knowledge. These studies have, in many cases, counter-posed expert and lay knowledges, either seeing these as equivalent (Williams and Popay, 2006), and thus offering an increasing challenge to objective and depersonalised expert knowledge; or quite different in value. For instance, both Prior (2003) and Collins (2014) consider lay knowledge to be the result of people's experiences, and while this makes them experts of a particular kind, they regard such experiential knowledge by definition to be idiosyncratic and not equivalent to the technical knowledge of scientific and medical experts. Other studies claim that lay and expert knowledges are not necessarily exclusive forms of knowing, but may be used in conjunction with one another. Wilcox (2010) for instance, points out that individuals develop 'broad cultural stocks of knowledge' which they utilise in their daily lives. These 'stocks' draw not only on "systematic, rational or scientific knowledge, but also on social ideas, religious beliefs, situated experiences and specific world views" (Wilcox 2010, p. 55). Experiential based knowledges have been the subject of much sociological

study (see Lawton 2003 for a review), and shown to be shaped by a range of different sources, with each offering different ways for people to come to understand, and give meaning to their illness (e.g., Davison, Davey Smith and Frankel, 1991).

Precisely how individuals develop and make use of their experiences to develop health-related knowledge is the subject of this paper. We propose that individuals produce health-related knowledge from a variety of sources as they experience the healthcare system and interact with health practitioners. These sources include the Internet, the media, friends and family. The emphasis of our investigations however, is on a form of knowledge that has been neglected in the literature thus far: system knowledge. To date, the focus of studies has been about people's knowledge of diseases and health conditions rather than knowledge about the healthcare system and how it operates. This appears to be an important, indeed crucial component of effective decision-making as patients navigate their way through the healthcare system. We theorise the knowledge process using Bourdieu's linked concepts of habitus, capital and the field.

Our Study and Methods

The study reported here is part of a larger project about the Australian healthcare system and the way in which patients navigate the pathways of this complex and increasingly privatised system. In this paper we focus on individuals' accounts of choice, the knowledge they draw on in their choices and, in particular, their choices between public and private healthcare. Purposive sampling (Barbour, 2001) was used to select 78 people with diverse experiences of healthcare, including those with both chronic and acute conditions, those who had used private and public services, as well as those with limited experiences of healthcare. We included people with and without private health insurance (PHI), living in different geographical settings (metropolitan, regional and remote) and from a range of age groups and socioeconomic backgrounds.

Following institutional ethics approval we conducted in-depth, semi-structured interviews between July 2013 and July 2015 in three Australian states. These interviews were aimed at gaining participants' perspectives of navigating the healthcare system, and the knowledge they used to make choices. Topics included use of public and private health services, perceptions of PHI, the role of social networks and sources of information in healthcare decision-making. Further discussion was encouraged through the use of a social map to visually represent the people or resources participants believed contributed to their knowledge of the system. Interviews lasted between 30 minutes and 1.5 hours (most lasted 1 hour) and were conducted with participants in their own homes, workplaces or another location of the participant's choosing. These were audio-recorded, with participants' consent, and fully transcribed.

Interview data were analysed thematically, and a coding framework developed collaboratively by three researchers. The framework was informed by the data as well as the relevant literature, and revisited and revised throughout the data collection and analysis processes. Data analysis workshops with all team members were conducted towards the end of data collection to explore key ideas, and decide whether further recruitment was needed. NVivo10 was used to assist with data management, organisation and initial coding.

Insert Table One about here

Table One provides an illustration of the diversity of the sample, with reference to age, including gender, ethnicity, education level, employment, income, household composition and PHI status. The 78 participants ranged in age from 19 to 90 years and comprised 28 men and 50 women. In the final study population, 37 had PHI (both hospital and extras); 11 with only hospital or extras; and 30 with no PHI at the time of interview. Of this last group, 16 (mostly older participants) previously had PHI. With regard to geography, 18 lived in a location classified as remote, 15 in a regional location, and 45 in a metropolitan area of a capital city. Participants had a diversity of illness experiences, with 45 participants described as living with a chronic condition or life limiting illness, some participants described very limited contact with healthcare providers, and others had on-going and extensive contact either for themselves or other family members. In the discussion below, we indicate the pseudonym, age of the participant, and whether they have PHI.

Bourdieu: Capital, Habitus and Field

Bourdieu's concepts of capital, habitus and field have been useful for the analysis of this data. We interpret the habitus to refer to a relational structure within which individuals' experiences become embodied. It is the means by which ideas and actions are patterned and made durable as we live and act within a given social context. The habitus, for Bourdieu, is an explanatory tool that shows how our actions are always historical, for our individual history shapes our thoughts and actions into 'durable dispositions' that guide future behaviour (Bourdieu 1993, p.86). It is within the habitus that various kinds of capital – both symbolic and material – are formed, and capital is simultaneously the resource individuals use to make choices and act, as well as the energy that provides the power to act (Moore, 2008, p.105).

Bourdieu's notions of habitus and capital are best understood in conjunction with his third major concept, the field. The habitus and its dispositions structure individual practice through the interplay and interaction of the various forms of capital, but the habitus is in turn structured by the dynamics of the field (Bourdieu and Wacquant, 1992; see also Wagner and McLaughlin, 2015). The field is the mechanism through which the various capitals are produced and socially distributed (Moore, 2008:105). It is always a site of struggle and contestation (Collyer, 2014), and a space of position-

takings (Bourdieu, 1983), with contests between the knowledge claims of differentially powerful actors. Understanding the healthcare sector as a field, in Bourdieu's sense of the term, enables close investigation of how individuals make choices, how these choices are shaped by the kinds of knowledge they bring to the medical encounter, and how such knowledges are intimately linked to the specific structures and organisation of the healthcare system they are faced with.

Findings

The stories told by our participants revealed a broad array of sources of information about health-related matters. As expected, they sought information from doctors and other health workers, the media, the Internet, families and friends. While medical knowledge remains important, participants discussed the expectation to draw on Internet sources to supplement their knowledge, as well as the significance of experiential knowledge in shaping their choices. Each of these is discussed in turn. We then turn to an emergent form of knowledge evident in participants' accounts – that of system knowledge – and outline two variants of such knowledge, acquired and assumed.

Trusting Medical Knowledge

Almost all participants discussed medical knowledge derived from their medical practitioner as informing their healthcare choices. The notion of medical authority as absolute was evident in Estela's account when she indicated that 'you pretty much do what your GP tells you to do'. For these participants, medical knowledge was linked with trust, but also the necessity of trust due, in part, to their lack of material resources and status in the healthcare field. Two participants with low income and ongoing health needs were Candice and Roger. Their comments are indicative of the need to trust medical knowledge:

If I had health issues I'd go to me GP, so I'd go there – GP... you have to trust them and you hope that you can trust them; that they're doing the right thing for you (Candice, 64, no PHI).

You trust that they'll be able to figure out basically what's going on and refer you to whichever specialist that you need to go to (Roger, 31, no PHI).

With little experiential or professional knowledge to draw on, Erin (32, PHI), also indicated the importance of relying on her General Practitioner for trusted knowledge – not so much the formal or clinical knowledge of the practitioner, but the informal recommendation that other patients have been satisfied with the advice provided, in this case about which specialist to see:

Yeah no experience in this type of thing so our GP had said that he'd referred a few people there and other people were happy with him so we just took his word for it.

The Knowledge Imperative: Participants and their Research

Although medical practitioners influenced choices made by participants, overwhelmingly participants referred to the additional work that was required of them to navigate healthcare – in particular, the importance of finding additional information about healthcare online. For example, Katie (44, PHI) discussed the importance of supplementing her doctor's advice with her own research. She described the work of doing this as a responsibility within the relationship with her doctor. Rather than passively accepting the advice provided in the medical interaction, she saw herself as an active player with possibilities for action:

My first point of contact would be my doctor, and then Google... gathering as much information as I can to understand what's happening, and that he knows what he's talking about... Then if he says to me 'oh, look, this is what we're going to [do], and I've read up on it, I'll say, 'could we investigate something else too. It could be this'... *It's more for me to give him the right information* so we don't go through the thousands of tests... *because I've researched. I've* done my homework (emphasis added).

Similarly, Morgan (29, PHI) described using Google prior to her appointment; but also signalled the importance of representing herself as an active participant in the process by undertaking research, even though the doctor ultimately was the arbiter of the knowledge that she gained:

As soon as something happens I go 'I better look this up, see what I'm dying of'. ... I have to say with me a lot of the times, because I've Googled a lot of stuff before I've gone to the doctors, I've often said to my GP 'I read such and such'. He'll say 'Oh no in this case it's not, or, yes that's common, that's true'. So a lot of it's because I do my own research (emphasis added).

Powerful ideas about the need to exercise individual responsibility combined with the availability of information on the Internet and, to a lesser extent, the perceived capacity to equalise the relationship between provider and patient were all dimensions intersecting to shape an individual's imperative to conduct healthcare research. The strategies participants drew on varied according to the type of decision to be made. For example, doctors were most important when participants needed a specialist referral, or were making a decision about a provider or a service. The Internet was often preferred when deciding whether to consult a doctor, or for other healthcare related decisions such as purchasing private health insurance.

Participants with a university education and in paid professional employment described the acquisition of such knowledge as part of the need to take responsibility for healthcare. For example, Michael (50, PHI) stated:

I've also realised is where you really have to also take your own health things into your own hands, that you don't purely rely on a doctor.

For participants describing undertaking extensive research, their commitment to self

responsibility was also linked with control – and participants were likely to privilege private healthcare options because in their view they could exercise greater control over their healthcare choices. For example, Kylie (41, PHI) stated:

Like when I was looking for that surgeon, that's precisely what I did. I looked at what their experience was, their standing, their profession and that was a Dr Google exercise and it worked out well for me. I have actually researched what he's done and whether or not he's the best person for what I want done....For me it's all about having an option to choose who I want to treat me.

The need to emphasise that they were acting responsibly in searching for healthcare information online was also evident in the way participants talked. When discussing the use of the Internet, participants emphasised that they were discerning in their approach. Almost all participants talked about using 'reputable' sources, discussing the importance of medically based or government sources. Others talked about their capacity to be discerning. For example, Paul (34, PHI) prefaced his discussion about undertaking research by stating his knowledge-seeking credentials:

Having my post graduate quals, I know the value of peer reviewed journals, going to a peak body and well referenced or researched sources of information. I mean Wikipedia is a great place to start, but it's then following up with the references, articles and colleges and things like that to drill down on it a little bit more.

Experiential knowledge

In addition to knowledge obtained from medical experts, and information from the Internet, participants also produced experiential knowledge that became highly valuable to them in their navigation of the healthcare system. This experiential knowledge developed in a range of ways. Those with long term conditions discussed the value of self knowledge, particularly where they were not satisfied with the medical advice they had received. Indicative was Kylie's (41, PHI) assessment of her migraines "I know my own body" and Damien's (58, PHI) on-going health experimentation with natural therapies for musculoskeletal problems: "I could nearly write a book on what works for me".

Experiential knowledge was also gained from the views, experiences and perceptions of family or friends. In some cases, knowledge gleaned from family and friends when selecting a health practitioner was also linked to the notion of trust. Family and friends were viewed as unbiased in the advice that they provided:

Because if you discuss about your needs to just say your friends or family and compare it with their experiences, you're able to siphon out what you want from that specialist. Whereas if you spoke to a GP, they probably just give you a general idea of who they would recommend or maybe a colleague that they know (Melanie, 49, PHI).

Experiential knowledge most commonly intersected with both medical authority and the individual research imperative. Many described it as a complex process of decision-making, depending on the problem, but underpinned by the importance of accessing the 'right information':

I probably would use my friends first. ... Yeah, because I don't quite often have much luck with doctors. I don't know, I guess if it's serious I'd probably go to the doctor first and then I'd Google it. ...sometimes I find you just Google until you find out what you want to hear. But no, a lot of it's quite useful. There's like WebMD and there's a few different ones that I feel like they're giving the right sort of information (Alice, 34, PHI).

While there were intersections across the various knowledge forms, patterns of knowledge were also evident. For example, a reliance on medical authority was most likely to be the primary source of knowledge for those participants with few other forms of knowledge to draw on. The importance of conducting individual research was evident mostly for participants who had evidence of cultural capital, for example, in the form of education generally, or professional expertise in health or science disciplines. Experiential knowledge was particularly evident for those who had personally experienced health conditions. However, it was evident that these knowledges were often not, on their own, sufficient to effectively navigate the healthcare system.

System Knowledge

Integral to navigating the healthcare field and overlapping with experiential knowledge is the notion of 'system knowledge'. In Bourdieusian terms, system knowledge is a particularly nuanced way of applying the often unspoken and sometimes invisible 'rules of the game' of healthcare. As Samantha (65, no PHI) said: "you've got to learn how to work the system. You make sure that you get the choices that are available".

System knowledge describes a form of knowledge applied to the navigation of the field of healthcare. Healthcare is a site where power relations are reproduced, and 'a person's experience in, and capacity to navigate, this field depends on status and position in these structures and relations' (Chang, Dubbin and Shim, 2015, p. 93). While most individuals develop some system knowledge of healthcare during the course of their lives, many are not able to apply such knowledge to secure advantage in navigation. Individuals are encouraged to trust experts rather than develop their own system knowledge, and there is more often a focus on learning about their own medical conditions than about the rules and operational dynamics of the healthcare field.

How is system knowledge gained? How is it constrained? In the healthcare system, system knowledge is difficult to develop given that it is strategically obscured in multiple ways. Experts, for example, may withhold knowledge about the system, as

the asymmetry of knowledge can be advantageous in a culture structured by decades of professionalism. This point has been well-argued since Freidson's (1973) work on the professions, showing that their prestige, power and capacity to control their own work and that of others is gained through, in large part, their control of specialist knowledge. Control over knowledge is not simply a strategy of the professions, but is entwined with other power regimes found in bureaucracies and in industry. For example, health insurance companies will provide information in a manner that is particularly difficult to understand, ensuring members will stay with their current plan due to the difficulty of comparing policies (Australian Competition and Consumer Commission, 2015).

At the level of interaction with healthcare providers, consumers increasingly need a repertoire of cultural skills, and verbal and non-verbal competences for successful interaction, and these in turn may shape the behaviours of their healthcare providers. Shim's (2010) notion of healthcare capital comprises in part a list of knowledges and behaviours enacted in healthcare interactions where the purpose is to gain advantage – these are not necessarily a calculated way of deployment, but rather a cultural means to achieve healthcare goals. She argues that consumers need a toolkit to enact strategies of action; this being a two-step process, whereby consumers need to acquire such knowledges and then convert them into actions that give them an advantage.

In our study, differential capacity to exercise system knowledge was apparent. As highlighted by Annabelle and Connor, being well-informed through research and having economic capital, does not necessarily give you knowledge about the healthcare system:

So, although I'm a well-informed university educated person I still didn't think to ask her those things and nobody prompted me. So it's curious. So how poor people without contacts and conversation with medical people get on, I don't know (Annabelle, 70, PHI).

Money's not my barrier. I have access to that and I'm very lucky in that regard. *It's knowing what the right thing to do* is and knowing how to do that (Connor, 45, PHI) (emphasis added).

Experiential knowledge can lead to the acquisition of system knowledge, particularly when acquired over time, and experienced across multiple healthcare encounters:

I feel very confident ... Last year was the first time in 37 years that we haven't had a period in hospital. So, I think I know quite a bit of what should happen and what doesn't. But other people, they don't (Eileen, 64, no PHI).

We've had enough contact with the medical system to know who the top specialists were in certain areas (Paul, 34, PHI).

Julian, a low income participant, with few resources to draw on, described using the Internet to acquire and then apply system knowledge to get his GP to provide a health

plan to access osteopathy: 'I read it on the osteopath's website that to get it free you had to have an allied healthcare plan, so that's why I went and got it ...' (Julian, 69, no PHI). This act did not occur in isolation – it relied on a disposition towards such treatment. Julian discussed previous positive experiences when he was younger through being treated by an osteopath, prompting him to seek information about access when he saw an osteopath sign on the doorway next to his medical practitioner. Thus, in agreement with Shim (2010), we argue that experience must be combined with disposition (habitus), and other attributes and skills in order for system experience to convert to the more valuable system knowledge.

While many participants described how system knowledge facilitated navigation of healthcare in quite small ways (as in the case of Julian above), one participant provided an extreme account of how privilege and system knowledge can combine and even enable movement outside the conventional 'rules of the healthcare game'. Economically advantaged, Internet savvy, a PhD in a health-related field and previous experience managing a large corporation brought together a multitude of capital resources. Living in a remote location, Ben (aged 71, PHI) described his response when diagnosed with prostate cancer:

So I got back home and said, 'I'm not going to wait months. I'm going to bypass the system', and I told my son who flew straight out [from another country]. We went to [capital city in a different state] to the top surgeon there, and said, 'we want to come here'. He said: 'the doctor is supposed to give a referral'. We said, 'we haven't got one, but we've looked you up on the Internet, and you're the top person, and that's why we've come'. ... And I know enough about the medical system to know that whenever a doctor gets treated, they always go to the best place. And I'm buggered if I'm not going to get as good a treatment as they do.

Assumed system knowledge and 'inside traders'

In contrast to the need to acquire system knowledge through the development of experiential expertise, searching online for relevant research or maximising advantage through exercising economic privilege, system knowledge can also be operationalized through social networks of privilege. While acquired system knowledge requires work on the part of individuals, often in the form of education and research combined with experience, assumed system knowledge requires networks of privilege (social capital) that can provide advantage in the healthcare system. For example, having been healthy all her life, and now confronting an on-going condition requiring specialist treatment, Annabelle (70, PHI) discussed her networks of privilege, acquired since university days. With close friends in a range of medical specialities, she described how she sought information from her networks to 'check the reputation' of medical specialists. She illustrated not only how she could draw on her networks of privilege, but how in turn these shaped her medical encounters. For example, she described how her GP "knows I've got a lot of doctor friends. She always asks me is there anybody you know you want to be referred to".

Nicholas' case also illustrates the existence of assumed system knowledge. He described his ease of access to specialist care when diagnosed with cancer:

One of my running mates was a gastroenterologist, and he said: 'You've got bowel cancer. I've got a mate whose the best that I've seen, *so I'll get you in* to see him'... So yeah, so I did have a choice, but it was because of knowing people that I got to see who I did (emphasis added) (Nicholas, 66, PHI).

Similarly Oliver (64, PHI) described the access that he could obtain to specialist care because his brother was a medical specialist. In his words,

...always draw on the networks: Yeah, there's no doubt I'd do that ... I suppose I've got back-up, which is sort of private, but it's insider trading.

In these instances, system knowledge is less about undertaking the work associated with navigating the healthcare system and more about having 'friends in high places' who can ease the passage into the healthcare system along with the assumption that these professional or personal networks were free of bias, thus ensuring the provision of best care. When discussing his adult son, Graeme (71, PHI) described the operationalisation of such networks and also the alignment of privilege with notions of private care:

I think they were in the process of probably scheduling him for operation and before that occurred we said "Okay we're going to get you down here in Sydney and find you somebody much better, we're going to use our contacts that we have, i.e. not only with the brother-in-law [a surgeon] but we have--we have a situation where one of my wife's cousins is a surgeon ... So we've got a lot of medical contacts. We brought my son down to Sydney, saw one of the best hand surgeons over in [name of suburb] one of the best ones in Sydney, and his advice was "Look it's in a very, very, very difficult position to operate in, even if I can get in there and operate." So the difference there is that by getting private health --by getting your own private doctors you're getting better expertise in my view.

In another example, Graeme illustrates this further:

What happened was there was going to be an orthopaedic surgeon undertake ...repair of his foot and we checked out who this orthopaedic surgeon was and the advice came back from [our contacts], other medical professionals 'anybody but him'. We went to the hospital and said to the people "We want a second opinion" and they said "You haven't even got a first one yet". We said "We don't care, we want a second one". .. [that's why the] need, in our view, for private medical.

System Knowledge and Public Versus Private Healthcare

Participants discussed choosing between public and private healthcare, suggesting various factors behind their perspectives. These included habituated understandings

stemming from the health habits of their respective their families. Ruby (25, no PHI) discussed her intent to obtain PHI as she was no longer included in her family cover:

Because my family has always had it, it feels like it's part of a normal functioning family that you would have private health insurance. I don't know any older people that don't have private health insurance. Especially not really anyone that would have families. So it kind of feels like one of those things that you need to get.

Similarly Lauren described the influence of her mother on her approach to healthcare:

My mum's advice is always see a specialist, just get - and so I do trust specialists ... I think that probably people that have been encouraged to see specialists by their family would probably then be more likely to seek that opinion when they're older and making decisions for themselves (Lauren, 30, PHI).

But the 'power dynamics', and what Bourdieu would refer to as the 'struggles within the field' also influence individuals' perspectives, either reinforcing their 'existing systems of dispositions' (Bourdieu, 1977) or serving to illustrate the desirability of dominant norms and values (Chang, Dubbin and Shim, 2015). Thus, other influences on participants' views of private versus public health include media coverage of public and private healthcare, policy directives regarding the desirability of PHI, and the marketing of PHI products. Illustrative of the role of the media as reinforcing dominant ideologies in the healthcare field, Kylie attributed her negative views about public hospitals to how they are portrayed in news media:

The perception of public hospitals, that's pretty much based on what you hear in the news. So I guess that has a negative effect (laughs). Because you only ever hear the bad stories, you don't really hear the good stories (Kylie 41, PHI).

Thus, general perceptions about 'the system' (usually referring to the public, rather than the private system of healthcare) were also widespread. In alignment with contemporary media and policy discourses, participants more often spoke critically about public than they did about private healthcare. While generally supportive of public healthcare, they questioned the capacity of the public healthcare system to cope with demand, and regarded this as driving the need to purchase private health insurance. Participants were also concerned about the perceived lack of choice within public healthcare, and this also situated their ideas about the desirability of private healthcare:

I think the health system, from what you hear, is not in good shape and it just seems that having private cover gives you that little bit more insurance that if you need help you'll be able to get it (Leanne, 70, PHI).

Participants were far less questioning of the private system, often viewing private

healthcare as an enabler of choice of doctor, more flexibility in timing for their procedures, and as providing more amenities (see also Cant and Calnan, 1992). In this way, private healthcare was seen as superior, because ideas underpinning the notion of the private sector are consistent with prevailing orthodoxies about choice and self responsibility. Ideas about the increased choice offered in the private system are illustrated by Kylie (41, PHI):

I guess to me, my belief is that...through private health you get to choose, I guess that to me is the difference and that is the point that matters to me.

In contrast, participants discussed the perception that there is no choice in the public system:

I just fear that I'll get to the time where my choices will be made for me and that will be to the detriment of my health. That really concerns me (Susan, 64, lapsed PHI).

Conclusions

In this paper we have described some emerging forms of complexity as individuals produce and utilise the knowledge they need to navigate the healthcare maze. In many cases, their knowledges about healthcare reflect an acceptance of the dominant notion of choice, the increasing imperative to take responsibility for one's health and a perception of private healthcare as superior to public. Bourdieu (1977, p. 85), points to the inculcation of such views which subsequently become durable dispositions (habitus), enabling reproduction of broader structures.

The choice about whether to use public or private is just one decision with which to contend. Participants in our study were actively negotiating between differing forms of knowledge and learning from their experiences. The evidence suggests that while authoritative medical knowledge remains important, there is now an imperative to research healthcare options and become an expert, active, responsible, fully-informed participant in all healthcare encounters. Moreover, there is an expectation that information must be gathered from a variety of sources to produce the knowledge needed, not just about health conditions and diseases, but about the healthcare system itself.

As Chang, Dubbin and Shim (2015, p. 96) argue, 'the healthcare field is characterized by distinctive norms and rules that are also reflective of larger social patterns of stratification', and thus rewards and status accrue more easily to those with capacity to navigate this terrain. Effective navigation of the healthcare system is more easily achieved by people with valued resources, skills and dispositions (Chang, Dubbin and Shim, 2015). We have posited the notion of system knowledge as being integral to navigation. Acquired system knowledge represents a form of knowledge available to those with education along with the capacity to work at gaining, and applying, appropriate knowledge. Many of our participants were in the middle aged group, were

working in emerging professional fields, and prided themselves on their capacity to be research oriented. On the other hand, those participants able to convert assumed system knowledge in order to meet their healthcare needs were generally socially and economically privileged, of older age, and more likely to be male than female. Thus the reproduction of social privilege within the healthcare system is evident in the form of assumed system knowledge. However this research extends knowledge of the navigation process by revealing a capacity to apply different forms of knowledge (particularly for those with research or health-related backgrounds) to also secure advantage within the healthcare system. Both assumed and acquired system knowledge combine resources such as economics, education and navigational skill, that can be used to obtain advantage in navigation of healthcare.

REFERENCES

Armstrong, D. (2013). Actors, patients and agency: a recent history. Sociology of Health and Illness, 36(2), pp. 163-174.

Australian Competition and Consumer Commission, (2015). Information and informed decision-making in private health insurance: *A report to the Australian Senate on anti-competitive and other practices by health insurers and providers in relation to private health insurance,* Canberra: Commonwealth of Australia

Barbour, R.S. (2001). Checklists for improving rigour in qualitative research: a case of the tail wagging the dog? British Medical Journal, 322(7294), pp.1115-1117.

Bourdieu, P. (1977). Outline of a Theory of Practice (R. Nice, translator). Cambridge. Cambridge University Press.

Bourdieu, P. (1983). The field of cultural production, or: the economic world reversed. In: Johnson, R., (Ed.) The Field of Cultural Production: Essays on Art and Literature. (pp.29-73). Cambridge: Polity Press.

Bourdieu, P. (1993). Sociology in Question (R. Nice, translator). London. Sage.

Bourdieu, P. & Wacquant, L. (1992). An Invitation to Reflexive Sociology. Cambridge: Polity Press.

Calnan, M. (1987). Health and Illness. London: Tavistock.

Cant, S. & Calnan, M. (1992). Using private health insurance: A study of lay decisions to seek professional medical help, Sociology of Health and Illness, 14(1), pp. 39-56.

Chang, J., Dubbin L. & Shim, J. (2015). Negotiating substance use stigma: the role of cultural health capital in provider-patient interactions, Sociology of Health and Illness, 38(1), pp. 98-108.

Chapple, A., Evans, J. & Ziebland, S. (2012). An Alarming Prognosis: How People Affected by Pancreatic Cancer Use (and Avoid) Internet Information Policy and Internet 4:2, pp.i-20

Collins, H. (2014). Are we all Scientific Experts now? Cambridge: Polity.

Collyer, F.M. (2014). Practices of Conformity and Resistance in the Marketisation of the Academy: Bourdieu, Professionalism and Academic Capitalism. Critical Studies in Education 56(3), pp.315-31.

Collyer, F., Willis, K., Franklin, M., Harley, K. & Short, S. (2015). Healthcare choice: Bourdieu's capital, habitus and field. Current Sociology, 63(5), pp.685-699.

Davison, C., Davey Smith, G. & Frankel, S. (1991). Lay epidemiology and the

prevention paradox: the implications of coronary candidacy for health promotion, Sociology of Health and Illness, 13(1), pp.1-19.

Dixon, A., Robertson, R., Appleby, J., Burge, P., Devlin, N., Magee, H. (2010). Patient Choice: How Patients Choose and how Providers Respond. London: The Kings Fund.

Frank, R.G. & Zeckhauser, R. J. (2009). Health insurance exchanges—making the markets work. New England Journal of Medicine, 361(12), pp.1135-1137.

Freidson, E. (1970). Profession of Medicine: A Study of the Sociology of Applied Knowledge Chicago: University of Chicago Press.

Gerber, B.S. & Eiser, A.R. (2001). The Patient-Physician Relationship in the Internet Age: Future Prospect and the Research Agenda Journal of Medical Internet Research, 3:2, e15.

Greener, I. (2003). Patient choice in the NHS: The view from economic sociology, Social Theory and Health, 1(1), pp. 73-89.

Hardey, M. (1999). Doctor in the house: the Internet as a source of lay health knowledge and the challenge to expertise, Sociology of Health and Illness, 21(6), pp. 820-835.

Harley, K., Willis, K., Gabe, J., Short, S., Collyer, F.M., Natalier, K. & Calnan, M. (2011) Constructing health consumers: Private health insurance discourses in Australia and the United Kingdom. Health Sociology Review, 20(3), pp.306–320.

Hesse, B.W., Nelson, D.E., Kreps, G.L., Croyle, R.T., Arora, N.K., Rimer, B.K. & Viswanath, K. (2005). Trust and Sources of Health Information: The Impact of the Internet and Its Implications for Health Care Providers: Findings From the First Health Information National Trends Survey, JAMA Internal Medicine, 165(22), pp.2551-2719.

Iyengar, S.S. & Lepper, M.R. (2000). When choice is demotivating: Can one desire too much of a good thing? Journal of Personality and Social Psychology, 79(6), pp.995-1006.

Lawton, J. (2003). Lay experiences of health and illness: past research and future agendas, Sociology of Health and Illness, 25, pp.23-40.

Levin, J. & Milgrom, P. (2004). Introduction to Choice Theory. Stanford University. California.

Moore, R. (2008). Capital. In: Grenfell, M. (ed) Pierre Bourdieu: Key Concepts. (pp.101–117) Durham, NC: Acumen.

Pescosolido, B. (1992). Beyond rational choice: the social dynamics of how people seek help, American Journal of Sociology, 97(4), pp.1096-1138.

Prior, L. (2003). Belief, knowledge and expertise: the emergence of the lay expert in medical sociology. Sociology of Health and Illness 25, pp.41-57.

Shim, J. (2010). Cultural Health Capital: A Theoretical Approach to Understanding Health Care Interactions and the Dynamics of Unequal Treatment, Journal of Health and Social Behaviour, 51(1), pp.1-15.

Taylor, D. & Bury, M. (2007) Chronic illness, expert patients and care transition. Sociology of Health and Illness 29, (1), pp.27-45.

Wagner, B. & McLaughlin, K. (2015) Politicising the psychology of social class: The relevance of Pierre Bourdieu's habitus for psychological research, Theory & Psychology, pp.1-20

Wilcox, S. (2010). Lay knowledge: The missing middle of the expertise debates, in Harris R, Wathen N, and Wyatt, S, eds, Configuring health consumers: Health work and the imperative of personal responsibility, (pp. 45-64), Basingstoke: Palgrave Macmillan,

Williams, G. & Popay, J. (2006). Lay knowledge and the privilege of experience. In Kelleher, D. Gabe, J., and Williams, G. (eds), Challenging Medicine. Second edition. London, Routledge.

Willis, E. (2015). 'Talcott Parsons: His Legacy and the Sociology of Health and Illness' in Collyer, F. (ed) The Palgrave Handbook of Social Theory in Health, Illness and Medicine. Palgrave Macmillan Houndmills, Basingstoke, Hampshire. pp. 207-221.

Ziebland, S., Chapple, A., Dumelow, C., Evans, J., Prinjha, S. & Rozmovits, L. (2004). How the internet affects patients' experience of cancer: a qualitative study BMJ: British Medical Journal 328: 7439, pp.564-567

Ziebland, S. & Wyke, S. (2012). Health and Illness in a Connected World: How Might Sharing Experiences on the Internet Affect People's Health? The Milbank Quarterly 90:2, pp.219-249

Acknowledgements

This work was supported by the Australian Research Council Discovery Grant (DP130103876), Australian Catholic University and the University of Sydney.

We wish to acknowledge other CIs (Professor Stephanie Short and Dr Kirsten Harley) on the project and also Senior Research Assistant and Project Manager, Marika

Franklin.

We also wish to thank all participants who generously gave us the time to talk about their experiences.