The Forms and Uses of Acquired Prostate Cancer Expertise Among Prostate Cancer Survivors

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Abstract
This article examines men’s prostate cancer experiences through the lens of patient expertise. Qualitative interviews were conducted with 29 men treated for prostate cancer, recruited from two prostate cancer support groups (PCSGs) in the South-East of England. Different forms of expertise, as classified by Collins, were found to be possessed by these men. How these different forms of expertise were acquired, used, and shared with others are explored, and a concept of communal licensing is posited to better understand these activities. The acquisition and usage of these different forms of expertise, through the employment of moral discourses that emphasise responsibility for one’s own health, are found to serve to blur the boundaries between lay person and expert.

Keywords
expertise, masculinity, prostate cancer

Introduction
Prostate cancer is the most common cancer in men in the United Kingdom (Cancer Research UK, 2019). There has been a range of clinical, nursing, psychological, and some sociological research on prostate cancer (Broom, 2009; Chapple and Ziebland, 2002; Fergus et al., 2002; Gray et al., 2000; Oliffe, 2005, 2009b). However, less attention has been directed to men’s experiences after more extended periods following treatment.

My research explores men’s experiences over extended intervals following prostate cancer treatment, as part of a broader research project exploring the question of how men maintain their masculinity following treatment. This article explores prostate cancer expertise for men who attended prostate cancer support groups (PCSGs), specifically exploring what levels of expertise they possessed and how they acquired this expertise.

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Patient expertise

Increasing access to health information over the last couple of decades has heightened the expectations placed on patients to be ‘expert patients’ (Ziebland, 2004) or lay experts. This is especially the case for those who experience chronic illness, where expectations for a person to self-manage and attend to their own health are high (Galvin, 2002) and where expertise about their condition is likely to build over time (Collins, 2014).

Prior (2003) identifies three themes in lay expertise research. Patient expertise has been conceptualised as experiential knowledge, where firsthand experience of illness provides patients with a unique understanding of their own situation (Busby et al., 1997; Monaghan, 1999; Thorne et al., 2000). Second, patient expertise has been valued equally with scientific expertise (Arksey, 1994, 1998; Epstein, 1996; Wynne, 1996). Finally, patient expertise has been understood as being produced by interaction within organised social groups (Brown, 1987; Brown et al., 2004; Rabeharisoa, 2003), where self-help groups have been identified as posing challenges to medical authority (Kelleher, 2006; Williams and Popay, 2006).

In Prior’s view, none of these elements are sufficient to qualify patients as ‘lay experts’. Prior (2003: 48) asserts that patient expertise is limited to the one specific case of the sufferer and may not reflect broader facets of the illness not present in every case; patients may be experts of their own bodies, yet this knowledge is ‘partial and limited’. An expert, in Prior’s view, not only requires substantial ‘expertise’ but also appropriate and relevant ‘license’ or qualification to give expert advice.

Collins (2014) has more recently provided a comprehensive framework for conceptualising expertise. According to Collins, we all have a variety of everyday, or ubiquitous expertises, such as speaking the native language of our country or tying our shoelaces, but specialist expertises, such as the practice of science, require specific forms of training to acquire. In his book, Collins refers to ‘expertises’ when describing different forms of expertise that he identifies, and the same practice is followed throughout this article. Addressing the problematic questions of whether we are all experts now, and if not, how do we decide which experts to listen to, Collins (2014) posits two categories of ‘specialist tacit knowledge’ (specialist expertise) that can help to distinguish a scientific expert, namely ‘contributory expertise’ and ‘interactional expertise’.

Contributory expertise is developed by learning heuristically from other experts and can be likened to an apprenticeship. Collins (2014) gives the specific example of chronic illness sufferers, arguing that they are not ‘lay experts’ but just experts, experts of their own experiences. They learn from medical practitioners, other illness sufferers, and personal experience of symptoms how to best manage their illness.

Interactional expertise is necessary to go beyond the narrow confines of contributory expertise. It involves learning the shared technical language of a field of study and being able to use it with fluency. This form of expertise allows scientists from different specialities to communicate their ideas with each other. Collins (2014: 68–69) asserts that while interactional expertise may not appear to be as substantive as contributory expertise, it is particularly important for the everyday conduct of scientific work.

Collins (2014) also identifies a sub-category of ‘special interactional expertise’ that is a ‘newly discovered one’ and constitutes a ‘small and very unusual group of specialist experts’ who
Acquire interactional expertise through occupying a strange role in which they immerse themselves in the discourse of a specialist community without fully participating in that community’s expertise. (p. 116)

Collins applies this category to people like himself, meaning researchers who study the practices of other research specialties, as well as to science writers and journalists. Extensive training to acquire both contributory and interactional expertise is required to become a specialist expert in a particular field of study, such as prostate cancer.

**Prostate cancer and masculinities**

Experiences of prostate cancer are shaped by masculinity. Prostate cancer has been identified as something that disrupts stable masculinities, where treatment side effects can impact on men’s sexual potency, continence, and energy levels, which can in turn present challenges to intimate relationships and working life (Broom, 2009; Chapple and Ziebland, 2002; Oliffe, 2005, 2006, 2009b).

Connell’s (2002, 2005) theory of masculinities (see also Connell and Messerschmidt, 2005) has become the dominant framework for understanding masculinities in relation to health and illness. Connell’s theory is compatible with a micro, interactional approach to sociology, yet accounts for macro structures in shaping masculinities. Hegemonic masculinity is the dominant form in Connell’s hierarchical order of different types of masculinities. Hegemonic masculinity is a relational concept, a symbolic ideal within a culture of masculinities (Connell, 2005: 77). Yet most men are instead complicit in the hegemonic order, strategically complying with hegemonic masculine conventions and aligning themselves with associated behaviours without necessarily engaging in them, thereby reaping the ‘patriarchal dividend’, which can yield ‘honour, prestige, and the right to command’ (Connell, 2005: 78–79). Hegemonic masculine values are dynamic, varying considerably at a local and a global level, yet common themes persist within Western cultures, such as having bodily strength, control and power, being self-reliant, unemotional, material providers, and prepared for violence (Connell, 2005).

Men’s relationships with masculine values, particularly in relation to health and illness, have a bearing on how men acquire and use expertise. Robertson (2006, 2007), exploring men’s health behaviours and attitudes, has identified that as men age their relationship with hegemonic masculine values changes. As a general trend, there is a transition over the life course, from seeking release and excess through activities that pose a risk to one’s health, and adopting a ‘don’t care’ attitude, in youth and early adulthood; towards taking more control over health and adopting more of a ‘should care’ attitude towards health. This is a transition that is fostered by men forming relationships and having children, and by societal pressure to be ‘good citizens’ and act responsibly in managing one’s own health (Petersen and Lupton, 1996; Robertson, 2006, 2007). Men in later stages in the life course are, therefore, generally more likely than younger men to have attitudes and behaviours that are receptive to using expertise for managing health and illness.

For prostate cancer, there has been little research exploring the acquisition and possession of patient expertise. Oliffe et al. (2011) found that PCSGs facilitate an increase
in men’s health literacy about prostate cancer. Through attendance at PCSG meetings, men came to understand prostate cancer using numerical test results and other clinical measures associated with the disease. This informed men’s discourse about prostate cancer and fostered a health consumerism approach to managing it. Such an approach was empowering for men by allowing them to align with but also at other times contest medical expertise, to secure what they considered to be the best treatments available for themselves. Oliffe et al.’s (2011) work shows that PCSGs facilitate health literacy for men, however does not explore this knowledge-building through the lens of patient expertise, which is explored in this article.

Research design

A qualitative, open interviewing approach was employed, using a topic guide with key themes as a basis for exploring themes without formulated questions but with some commonality between interviews. The flexibility accommodated by open interviewing facilitated addressing sensitive topics, by being able to return to them over the course of the interview and approach them from different angles (Fielding and Thomas, 2008; Mason, 2002). Open interviewing involves active listening, where keen attention is paid to what the interviewee is telling the researcher and what issues are important to them (Noaks and Wincup, 2004).

The sample was achieved by theoretical sampling, based on the principle requirement that the men recruited had previously been treated for prostate cancer, a prerequisite criterion checked with interviewees prior to interview. Over 6 months, beginning in June 2014, 29 men were recruited from two PCSGs in the South-East of England. In September of the same year, I attended a group meeting of Support Group 2 to bolster a declining level of recruitment, which was sustained until December when a point of data saturation (Charmaz, 2014) had been reached, where new interviews were no longer yielding new topics of discussion. The ethical approach was developed in accordance with university ethical guidelines and received favourable ethical approval prior to commencing fieldwork from the author’s departmental ethics committee.

Interviews began with broad questions about employment, family life, and general health, to ease participants in to the interview and to encourage them to talk freely and without much prompting (Oliffe and Mroz, 2005). Masculinity can be a barrier to data collection within interviews (Schwalbe and Wolkomir, 2002). I sought to reduce any sense of competition with interviewees, adopting a respectful, deferential attitude by giving them space at the beginning of interviews to speak without extensive probing or questioning of men’s accounts. However, I equally sought to challenge the accounts men gave and not take them at face value, particularly later during interviews once rapport had been established. To tread this balance, I sought to foster a student-teacher dynamic, relying on my comparatively younger age in my mid-20s to participants’ ages ranging from early 50s to early 80s. This allowed me to query men’s accounts but from a position of wishing to learn from someone more experienced, rather than questioning their factuality.

Young interviewers have been found to lack a more conversational style and be less willing to share their own experiences within interviews (Manderson et al., 2006) and I
sought to address this by adopting a conversational and open approach to interviewing that included offering my own stories and reflections within interviews, sometimes in relation to myself or my father, or sometimes to my grandfather’s prostate cancer experiences, which inspired my research interest in this topic. A conversational approach encouraged men to be active within interviews, to break away from the medical consultation model of health talk men traditionally engage in (Oliffe, 2009a).

The age range for the men interviewed was between 53 years and 83 years, with more than 60% of the sample being in their late 60s or early 70s. All but two of the men were married, one being widowed and one divorced, and all self-identified as heterosexual. All but one of the men were currently or had previously been employed in skilled professions, often in technical and scientific fields, or senior managerial roles. All the men interviewed were White British or White European. More than half the sample had a radical prostatectomy as their primary treatment and just under half had radiotherapy either as a primary or secondary treatment. The interviews generally lasted between 1 and 1.5 hours.

More than half the sample had received primary treatment within the last 5 years at the point of interview, with the longest interval since primary treatment being 15 years. However, many interviewees received secondary prostate cancer treatments and other procedures for managing treatment side effects, so such intervals do not accurately reflect men’s ongoing concerns related to their prostate cancer. Importantly, the data collected are subjective reflections on past events, inevitably relying on recollection and being framed through interviewees’ current situations. This is a key limitation of the study, however men frequently kept health records of their cancer experiences and these were directly referred to as reminders during interviews. Furthermore, the variety of time intervals at which men were interviewed following primary treatment provides a means of exploring common post-treatment experiences, which was a key aim of the study.

A thematic approach to coding was undertaken, where data collection and analysis led to the identification of common themes that guided later interviews and contributed to a data-driven analytical process. The construction of data is understood as a joint process of meaning making, and data are interpreted and re-interpreted over the course of the research. Interpretation and analysis of data is accordingly ongoing throughout data collection, as part of a reflexive analytical process.

Findings

The men in this research were found to possess two important forms of specialist knowledge required to be an expert: contributory and special interactional expertise (Collins, 2014).

Contributory expertise

Contributory expertise was acquired through experience of having prostate cancer, treatment for it, and through managing associated conditions resulting from treatment, over extended periods of time.
William’s account describes his need to urinate, a result of his reduced level of continence from his radiotherapy.

William I can go normally for about two hours, before I have to pee, and I produce a reasonable quantity of urine, but not as much as possibly I ought to, the problem is that I go so frequently, that I’m-I keep off coffee, quite a bit

Interviewer Certain things are a trigger?

William Coffee does trigger me off, more rapidly than other things, it doesn’t matter if I’m within reach of a loo (aged 83, Radiotherapy with Hormone Therapy, Architect)

William discovered through experience that coffee sets off his incontinence, ‘more rapidly than other things’, sometimes so rapid that he has been unable to reach the toilet in time, something he has learnt through personal experience. William is no longer total master of his own body, over time he has come to know his changed body and become an expert of his urinary function; understanding the time limits he can reasonably impose on his body and knowing how his body responds to certain external influences, such as coffee. William has developed contributory expertise through his experiences, which assists him in monitoring how and when he urinates.

Contributory expertise can also involve learning through and with other patients and medical practitioners. Clive also had continence difficulties yet, in seeking to prevent bladder retention, Clive would self-catheterise daily to maintain his level of continence. This involved inserting a catheter up his urethra and into his bladder to pass urine:

The first ones I used way back were rather flexible, I think about size 12 or something, and as you push them they kink, so the ones I used at first, you had to hold the end, because the others have got the bloody lubricant on . . . now I have got new catheters, and the specialist nurse there who was teaching to me and showing me and explaining, gave me an option of which ones you would like, and I chose the one which has a gripper, what you call a gripper on it, and you can actually hold it, you can hold it closer to the tip or closer to your organ, your gland, and which means you’ve not got too much of this in (referring to a catheter in his hands), and that’s where you can apply a bit of pressure. (Clive, aged 76, Radical Prostatectomy, Radiotherapy, Electrical Engineer)

This technique involved a skill developed over time, which Clive learned partly through his experience of his own body but also partly through the specialist nurse teaching him the technique. By changing catheter, Clive found a better way to hold and position the catheter – a skill that was developed with practice and through trial and error. This was not a change dictated by a medical practitioner but instead met with Clive’s needs on which he was an expert, more so than the medical practitioner who lacks the specific expertise that comes from experiencing the symptom firsthand.

William and Clive’s accounts illustrate how men possessed contributory expertise in relation to their prostate cancer experiences. Men can become experts of their ill bodies through their personal experiences of illness. Furthermore, they can develop contributory expertise by learning from and with medical practitioners to employ or appropriate medical practices in the management of illness.
Special interactional expertise

Anyone who experiences prolonged illness might be capable of developing contributory expertise to some degree, yet interactional expertise is more difficult to acquire. Interactional expertise is ‘acquired by engaging in the spoken discourse of an expert community to the point of fluency but without participating in the practical activities’ (Collins, 2014: 68), the practical activities in this instance being the practice of medicine. A familiarity and engagement with this discourse was evident in men’s talk in this research. However, accumulating interactional expertise requires extended periods of time working with other specialists in one’s field and interacting and communicating with them, using the technical language of that field, on a regular basis. Instead, a combination of clinical encounters and encounters with medical practitioners and other patients and survivors at support group meetings were key to the acquisition of expert discourse for the men in this research. This arguably went beyond a level that might be expected to be acquired in the course of simply managing prostate cancer illness and instead was extensive and broad in remit. However, men’s expert discourse in this research is understood not as ‘interactional expertise’ but as ‘special interactional expertise’ (Collins, 2014), discussed further below in this section.

The commonly high degree of comprehension and utilisation of medical language among the men interviewed was frequently illustrated by the interviewees checking with me, the interviewer, if I understood the technical terms they were using:

They said nerve-sparing surgery, I think on this-do you know much about this Da Vinci machine? (Matthew, aged 77, Watch and Wait, Radical Prostatectomy, Radiotherapy, Sales)

So I had a PSA check done, it was 4.2, which is-do you know about PSA? (Jamie, aged 53, Robot-Assisted Radical Prostatectomy, Engineer)

Men also possessed specialist prostate cancer expertise beyond that which may be required for the management of their illness. This is evident in Robert’s account below, where he expresses his understanding and opinions of the long-standing controversy over whether it is beneficial to screen for prostate cancer:

I think there ought to be a lot more screening than there is . . . there are so many false positives, as I say false positives are a major problem. It’s just not that simple, if its high-I reckon if its high (referring to PSA level) and you’ve got other suspicions then you need to go for a test. (Robert, aged 67, Radical Prostatectomy, Information Technology Consultant)

Robert’s account demonstrates a nuanced understanding of the issues involved within the screening debate. This expert knowledge goes beyond what is necessary for managing prostate cancer illness, as screening is a broader issue of public health. This raises the question of how men come to possess such knowledge, which would not likely be learned during interaction with medical practitioners within clinical encounters.

The two support groups from which men were recruited both hosted regular monthly meetings with invited speakers, predominantly medical professionals, coming to speak about their field of specialist expertise. There were time-periods before and after these
presentations for men to speak with not only other attendees but also potentially with medical practitioners who had come to speak. There were also opportunities to ask questions to speakers following their talks.

Oliffe et al. (2011) identified how men learn ways to contest and align with medical experts through their interactions at support groups. Extending on this, my research identifies how access and contact with medical practitioners through support group meetings, beyond the clinical encounter, enabled men to immerse themselves in the shared technical language of medical research on prostate cancer. By being around experts on a regular basis and immersing themselves in the medical terminologies and practices of medicine, these men were able to develop a ‘richer type of expertise’ (Collins, 2014: 68), one which with time would allow men to pass as experts in the field of prostate cancer. However, this is not considered to be interactional expertise to such a degree that we might compare these men’s expertise to that of medical professionals, but rather is considered as ‘special interactional expertise’ (emphasis own). This is because men immersed themselves within the discourse of medical practitioners yet did not ‘fully participate’ in the community’s expertise, because they were not urologists or other medical practitioners whose everyday working lives concerned the study of prostate cancer. This ‘strange role’ (Collins, 2014: 116) that these men occupied demonstrates that they possessed special interactional expertise.

Factors facilitating the acquisition of specialist expertise for prostate cancer

Within this research, factors are identified as playing a role in facilitating the acquisition of specialist expertise for prostate cancer. These factors are the possession of ‘referred expertise’ (Collins, 2014) acquired from men’s paid employment and from having a technical interest in scientific ideas and processes, which are discussed in turn.

Many of the men interviewed for this study had developed skills in their working lives that they subsequently applied in the pursuit of specialist expert knowledge of prostate cancer. Collins (2014) asserts that

Almost everyone who works for a living has a specialist expertise: an expertise associated with the training and experience they gain in doing their specialist job. (p. 117)

All the men interviewed in this study had their own specialist expertise that they had developed from their paid employment. Importantly, two-third of the sample were currently or had previously been employed in a managerial role, the majority within mathematical, science, and/or engineering sectors.

The managerial roles that these men were engaged in are important because the managerial expertise that they possessed can be understood as ‘referred expertise’, a ‘substantive technical expertise’ (Collins, 2014: 77) from one specialist area that is used in another. The interactional expertise that managers possess, to converse using the technical language of their employment sector, is transferrable and referable in facilitating an understanding between different specialist areas. Referred expertise facilitates the acquisition of new specialist expertises.
Another common theme from men’s accounts is the interest often expressed in technical processes and scientific ideas associated with the medical management of prostate cancer and treatment side effects. This technical interest is considered another important facilitator in the acquisition of specialist expertise for prostate cancer, as without it the motivation to develop expertise further than what men are told by their doctor would be weaker. This motivation was particularly evident in the accounts of the men who were or had been employed in technically specialised professions within scientific industries such as engineering or electronics. Even for some men who did not end up working in scientific industries, their educational backgrounds were often science and engineering focussed, through apprenticeships or university degrees.

To illustrate this theme, Jamie here describes the sensations of his erectile dysfunction:

You need that extra, bit of-pumping your tyre up, it’s those last few pumps that really makes the difference, so it’s like a, like a sink, you turn the tap on, you’ve got the plug in, it fills up, but my plug is sort of only half in, so the bloods pouring in, but it’s also pouring back out again. (Jamie, aged 53, Robot-Assisted Radical Prostatectomy, Engineer)

Jamie uses mechanical metaphors to convey the functioning of the body, likened to the filling of a sink or the pumping of a tyre. Jamie later says, ‘how the body generates that kind of pressure is pretty clever really’, which further illustrates his interest in the biological functioning of the body.

Lucas, too, has a keen interest in medical processes, describing in unsolicited depth, how the process of radiotherapy works:

It’s extremely accurate, they don’t do wide areas of radiotherapy with a lot of scatter damage, again because this is something also with long term repercussions and radiotherapy is- the area will be traumatised, the tissue, it won’t heal, or respond to surgery or other repairs ever as well again, and they put three- now its five beams in. (Lucas, aged 66, Robot-Assisted Radical Prostatectomy, Engineer/Risk Analyst)

Lucas’ account shows an interest beyond just the efficacy of the treatment but also an interest in the scientific processes that underpin radiotherapy, evident in the detail with which he describes them.

Both Lucas’ and Jamie’s specialist expertise from their paid employment has shaped their orientation towards acquiring prostate cancer expertise. They are interested in understanding the scientific processes related to prostate cancer and this interest is shaped by their experience in technical professions within specialist scientific industries. These accounts provide some explanation as to why these men’s specialist prostate cancer expertises are more considerably developed beyond what might be expected in the acquisition of prostate cancer knowledge simply for the management of the illness.

Having identified the specialist expertises for prostate cancer that men possess and considered what factors might facilitate the acquisition of these expertises, the questions remain of what ‘license’ (Prior, 2003) men possess for their expertise and how they use this expertise. These questions are considered in the following section.
Communal licensing of prostate cancer expertise

It has already been posited that support groups play an important role in facilitating the development of expert prostate cancer knowledge and spoken discourse. However, support groups also play an important role in men’s acquisition of contributory expertise. Support groups served as sites where men could share their contributory expertise with other men.

There was a common emphasis among the men interviewed that they felt they were not able to give ‘medical advice’, yet instead, they were able to share their own experiences. This provided a new perspective for other men to help them to better understand the experience of prostate cancer, as Peter’s account illustrates:

Peter: I joined the cancer support group to help other [people] and so if somebody comes to us and asks- so I saw a bloke a couple of weeks ago, he was about to make up his mind, of what one he wants, I don’t give them medical advice-

Interviewer: No, you just tell them about your own experiences (repeating what Peter has said earlier)

Peter: Yes, well the surgeons are great at what they do, but unless you’ve been through it you don’t know what the things are like (aged 72, Radical Prostatectomy, Radiotherapy with Hormone Therapy, Engineering Manager)

Over time, Peter’s role changed from primarily seeking to acquire prostate cancer knowledge to seeking to share knowledge with others. In this way, men were able to pass on their specialist knowledge as it pertained to them and others around them. This expertise is different and unique compared with the expertise that doctors can provide because it is based on personal experience of illness.

PCSGs play an important role in legitimising the giving of advice to other men and defining the boundaries of what advice can be offered to and by men attending support groups, as Geoff’s account shows:

I’m not supposed to give advice, but I do give advice to men in the group when they tell me their PSA is high, I say go back and get it done again, you know that’s what we’ve got on our thing (support group produced information literature), to say that we can’t give medical advice, well we can’t, I’m going to give my advice, my experience. (aged 67, Radiotherapy with Hormone Therapy, Telecommunications Manager)

Someone must possess ‘license’, in the form of publicly recognised and validated qualifications, to be a true expert (Prior, 2003). Becoming closely associated with a support group over an extended period provides a degree of legitimacy from which to offer contributory expertise to others. The limits of that advice are established within support groups and a shared sense of the limits of what advice can be given is learned within these settings, as Geoff’s account illustrates, where described aims to seek to provide ‘information’ and ‘awareness’ about prostate cancer provide a grey area where men can take on limited expert roles. Licensing of expertise here is a communal process of validation or legitimation provided by and within PCSGs. This process involves
curtailing the limits of that license. The giving of ‘medical advice’ is restricted but the sharing of experiences for the purposes of providing ‘information’ or ‘awareness’ is encouraged.

Chris felt a desire to ‘give support to others’ and this was a common sentiment among the men who engaged in sharing expertise with others. Such accounts have an implicit morality, of doing the right thing and emphasising the importance of responsibility for one’s health. These kinds of moral discourses are demonstrated in Clive and Lionel’s accounts below of providing advice to men beyond support group settings:

There’s another neighbour . . . with a relatively high PSA, so, I mean I’ve talked with him, I tried, but it’s impossible, you can’t force people to have a PSA, but you can explain to them. (Clive, aged 76, Radical Prostatectomy, Radiotherapy, Electrical Engineer)

I mean I introduced a couple of people-(to the support group), I’ve got a client who says I saved his life, he came to see me one day . . . I said, ‘but have you ever had your blood test’, and he said ‘no?’, and I said ‘well the reason I asked’, I said, ‘I might be totally out of order’, I said, ‘we’ve been together three quarters of an hour and you’ve been to the loo twice’, ‘arghh’ he said, ‘its murder’, he said ‘I’m up four times every night’, and I said ‘well can you do me a favour, can you have your blood test’. (Lionel, aged 66, Radical Prostatectomy, Chartered Accountant)

Clive is advocating for his neighbour to have his PSA checked and take responsibility and ownership of his health, and to act in a way that he believes will be better for him. He is using his expertise to take a position of a ‘moral advocate’ (Green, 2019) for his neighbour, a specific configuration of identifying with masculine values where he is presenting himself as in control and as caring about his health. Lionel’s account reports how he ‘saved’ a client’s life through his imparting of advice. The phrasing is in friendly terms, as between peers, of asking his client to ‘do [him] a favour’ by getting tested, but his association with his support group provides him with the authority (derived from a space that arguably has a social acceptability and legitimacy) to give his advice as a ‘moral advocate’ (ibid) beyond the support group setting.

This support group-derived authority was, within Support Group 2, formalised in the activities organised by the group outside of their regular meetings, as Edward’s account describes:

We grab men by the throat, if they’re of the right age, passing, and tell them to get themselves tested, basically, that’s what it’s about. (Edward, aged 79, Radiotherapy with Hormone Therapy, Manager for British Rail)

Edward here describes a community outreach event to raise awareness about prostate cancer at a local town centre. Such events provided another opportunity through a more structured format for men to be able to share their expertise in a legitimate way. The ‘license’ (Prior, 2003) men possess is further legitimised here, as they have been given permission to set up a stand from which to share expertise with strangers in a public venue.
Discussion

The men in this research can be understood as being ‘savvy social actors’ (Brown et al., 2004: 64) by aligning themselves with medical professionals and engaging in communal practices of knowledge sharing and expertise legitimising, thereby, blurring distinctions between lay and expert knowledge. The special interactional expertise they possess marks these men out as having remarkable levels of expertise, beyond what Collins anticipates for lay people. Furthermore, while the men in my research possessed no formal ‘license’ (Prior, 2003) for their expertise, they communally produce their own license within PCSGs as a means of legitimising their knowledge sharing with others, termed here as communal licensing, which problematises Prior’s (2003) demarcation point between lay person and expert.

Blurring the lines between lay person and expert involved men not representing their knowledge as ‘expertise’ but rather as ‘advice’ or ‘awareness’. The men in this research were able to circumvent the problem of overstepping their ‘license’, as their expertise was referred to either in terms of relating personal experience or was couched in the moral language of information you should know or should make yourself aware. An informal process of regulation of how expertise was shared occurred within PCSGs. Furthermore, while no formal licensing is offered by state institutions for men at PCSGs, which a medical doctor is licensed by (this is the specific example of licensing that Prior refers to), there have been no state actions to curtail PCSG activities (Faulkner, 2012) in providing or limiting expertise, likely due to gaps in care provision for men following treatment for prostate cancer that the state relies upon voluntarily run PCSGs to fill (Kelleher, 2006).

Men have advised other men by drawing on their own experiential knowledge to inform others and have employed moralising language to give credence to their actions. By doing this, men’s expertise is not treated as ‘objective’ knowledge but rather is value laden, the sharing of expertise with others becomes a moral good, a way of ‘giving back’, and advice is framed within a broader societal discourse of responsibility (Robertson, 2006). Using their expert knowledge, these men perpetuated moralising talk about the importance of health responsibility for men, a discourse that is embedded in the ‘informed choice’ model of prostate cancer decision-making, advocated for and by men with prostate cancer (Faulkner, 2012).

Conclusion

This research finds that practices of communal licensing and sharing expertise through moral discourses that encourage men to be responsible for their own health serves to strengthen these men’s positions as lay experts. While it may not be justified to refer to the men in this research as ‘experts’ by definitions set by Collins (2014) and Prior (2003), the men in this research, while being a rather unique case, illustrate how lay people can acquire significant expert knowledge and use that knowledge like experts. Men’s practices of communal licensing and sharing of expertise, activities that can mimic those of practicing prostate cancer medical practitioners, warrant further research attention, particularly exploring the prevalence of such practices among other groups with chronic
illnesses and more heterogeneous samples. This research is limited by the homogeneity of the sample of white middle-aged older men, characteristics that arguably have been key to shaping the practices these men developed as a group. A different interviewing and analytical approach, such as narrative rather than the thematic approach employed, would also help to address the limitation of not identifying the histories of the participants and how these histories shaped men’s experiences and activities in relation to their masculinity and lay expertise building prior to prostate cancer diagnosis and treatment.

An important absence in men’s accounts was their emotional experiences. Attempts to probe men’s feelings about their cancer experiences were often met with prolonged silences, short and deflecting answers, and subject changes by the interviewee. It is possible that due to many of the participants of this research having had treatment long before being interviewed, the normalisation of their experiences had already taken place and emotional experiences were difficult to recall, drawing instead on familiar repertoires, acquired and rehearsed through attendance and engagement with PCSGs, emphasising values of knowledge and expertise they were familiar with. Further research with men soon after treatment is required to better understand men’s emotional experiences in relation to prostate cancer, to better understand the interplay between emotions, masculinities, and expertise, to build on a growing body of literature in these areas (Oliffe et al., 2011; Robertson, 2007; Robertson et al., 2010; Simpson and Richards, 2019).

This research identifies that beyond previously identified benefits of PCSG attendance, PCSGs can also facilitate the building of communal networks of prostate cancer expertises, where such expertises are regulated and shared. The implication of these findings for health policy is in recognising the value that such information networks within PCSGs can provide as an important resource for men throughout the trajectory of prostate cancer, from diagnosis and beyond this point, and seeking to capitalise on and make better use of these networks.

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