Producing communal health through technological self-care: the emergence of digital patient activism

Sub-theme 68

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Abstract

This study shows how patients co-produce health knowledge when they use digital technology (such as health apps and online platforms) to manage their health and the implications technological self-care has for communal health. It presents results from a qualitative study that took place in the English healthcare context and involved a range of stakeholders such as policy makers, patient organisations and patient experts, and health IT developers (e.g. health apps). The paper moves away from how patients use digital interfaces to 'consume' information towards how they are 'activated' on the basis of the information they have consumed or created and the implications of their activation for others. We argue that a care for the other emerges when patients self-manage their health through technological interfaces. We name this phenomenon digital patient activism and show that this is an unintended effect of self-care (albeit a conditional one), which although associated with a neo-liberal discourse that assumes self-responsibility merits attention and recognition given the value it creates for the community.

Keywords: activism, patienthood, digital technology, UK

1 Introduction

Our study is situated in the literature that examines the ways in which patients (co-)produce knowledge as they engage with digital technology. In the light of this literature some studies have looked into how the information patients produce, like for example their experiences of healthcare delivery, is used to improve products and policies (Adams, 2011); to provide care (Radin, 2006) and to monitor and gain a better understanding of one's health (Lupton, 2016). Other studies have emphasized on how value is created and leveraged in online health communities (Barrett et al., 2016; Osei-Frimpong et al., 2016) - including commercial and business value (Lupton, 2014) - how patient-reported health data transform medical research and expertise (Kallinikos and Tempini, 2014) and how they could lead to forms of activism (Radin, 2006). This study aims to show how patients produce health knowledge when they use digital technology (such as health apps and online platforms) to manage their health and more importantly what the implications of technological self-care are for communal health. We argue that a care of the other emerges when patients self-manage their health through technological interfaces. We name this phenomenon digital patient activism and show that it is an unintended effect of self-care (albeit a conditional one), which although associated with a neo-liberal discourse that assumes self-responsibility merits attention and recognition.

The remainder of the paper is organized in the following way. Next section describes the shifting nature of patienthood and how different conceptualizations of patient identity condition health activism. The subsequent section outlines our methodology, which is followed by a presentation of our findings. The penultimate section discusses our research vis-à-vis relevant literature and some final conclusions are presented.

2 The Shifting Nature of Patienthood & the Emergence of Health Activism

NHS reforms over the course of the eighties and nineties introduced the notion of the patient as a consumer and the healthcare sector as a quasi-market. This was ostensibly in order to enhance patient choice for instance the choice of treatment from a range of alternatives (Schüll, 2016). Closely associated with the idea of patient choice is the portrayal of the patient since 1990s as an 'informed consumer' (Henwood et al., 2003; Henwood et al., 2011). With the additional possibilities the Web 2.0 offers to citizens the above portrayal of patients has given way to the 'reflexive' (Adams, 2011) and to the 'digitally engaged' (Lupton, 2014) patient. Reflexivity and engagement suggests that patients are actively participating in their healthcare conduct by not merely consuming information given to them but also actively seeking for meaningful information and publicizing information that matters to them and perhaps to others (Adams, 2011). Barrett et al (2016) has shown for instance how patients in online communities create epistemic value by producing health-related knowledge such as online ratings of specific healthcare providers, information about medical conditions through the sharing of experiences and knowledge about disease profiles. Patients' engagement is said to gradually blur the boundaries between the medical expert and the lay patient (Barrett et al., 2016; Kallinikos and Tempini, 2014).

Scholarly work has been critical of the above conceptualisations of the patient. Adams (2011) suggests that the reflexive patient is not an identity we choose to perform but is an expectation of what we need to be doing as good citizens-patients. Patients' autonomy is restricted further by the design of the technology and the way it structures how and what type of data patients can input and share online. Some form of moderation and editing is expected to ensure good quality of information and patients'

input is often subject to approval by a medical expert (Adams, 2011; Kallinikos and Tempini, 2014; Tempini, 2015).

Our study is situated at the intersection between digital health technology and patient activation, looking more specifically into how the technologies patients choose to use for their self-care end up producing healthcare knowledge that has beneficial implications for communal health too. We call this phenomenon digital patient activism. Health activism has typically been associated with groups (such as patients' organisations) that construct an identity around a specific disease (or healthcare more broadly) and take action on the basis of this identity (Epstein, 1995; Landzelius, 2006). An institutional, formal and top-down character is attributed to them. Actions are directed towards intervention in clinical trials and methodologies and towards the production of clinical/medical knowledge (Rabeharisoa et al., 2014). Radin's study (2006) has shown that forms of activism may also emerge from online patients' communities. Our study intends to contribute to the above studies by showing how activism emerges in the digital world as an unintended consequence of patients' self-management of their care. We take a non-institutionalized approach to activism. Activism refers here to the productive power digital technology has to facilitate self-care leading to the production of communal health. Our study shows that activism emerges from patients' co-creation of epistemic value. This in many cases extends the use of information for personal purposes such as involvement in clinical decision making (Osei-Frimpong et al., 2016) and refers to the production of knowledge that can be of use to other stakeholders such as patients (Barrett et al., 2016), healthcare professionals and IT designers.

3   Research Methodology

The paper draws upon a qualitative interpretive study that aimed to investigate the role digital technology plays in enabling patients' self-management of their health. Given the broad and complex landscape of health technology, we restricted our focus to digital health interfaces such as patient online platforms and health apps and excluded other medical devices that are used for the management of chronic diseases such as insulin pumps. The study aimed to respond to the following question: How does digital health technology enable patients to manage their health and care and what are the consequences of such usage for others?

The study took place between August 2014 and May 2016 and focused on the English healthcare context within and outside the boundaries of the National Health Service (NHS). We gathered information through the collection and analysis of documents and through semi-structured interviews. Specifically, we conducted 31 interviews with three main stakeholders: health policy makers (such as NHS England; Health and Social Care Information Centre (HSCIC); National Institute of Clinical Excellence (NICE); Digital Health and Care Alliance (DHACA); National Data Guardian); patients, patient organisations and organisations working for patients' interests (such as Parkinsons UK; Diabetes UK; Patient Opinion; HealthWatch; Patient Information Forum etc.) and digital health technology experts working in the area of the development of apps and patient platforms. We also collected relevant health policy reports published by the Department of Health, NHS England, HSCIC and other documents such as newspaper articles, documents provided by participants, reviews of relevant websites etc. We designed and conducted our research according to the research governance frameworks set by our institution and our funder and received approval by our institution's Research Ethics Committee. We analysed our findings following a thematic process and used NVivo to organize the information we collected and establish relations between themes.

4   Findings

Our study shows at least four different forms of digital patient activism. These forms refer to the ways in which patients co-produce health-related information (e.g. health data; feedback; narratives of health experience; advice; applications) when they use digital interfaces to manage their health and how this leads unintentionally to the improvement of communal health (e.g. improvements in healthcare delivery; education and training; peer support; innovation etc.).

Specifically, findings from our research suggest that patients become contributors to the production of large amounts of health-related data that are used for clinical research purposes. Big data are collected as patients add information to digital health interfaces about their diagnosis, condition, treatment, side effects and lifestyle choices on top of other demographic type of information they add when they sign up to use a health app or to participate in an online platform (age, smoking status etc.). The collection of longitudinal patient-reported outcomes is vital for medical research to understand how patients respond to treatment.

The amount of information patients feed in the technology is dependent on the frequency and level of usage they do as well as the stage they are in their health journey. Often however it is also dependent on the perceived purposes data collection serves. Our study suggests that patients find meaningful the collection of personal health-related data for clinical research purposes and support it by making more eager use of it. A developer of a health app intended for breast cancer patients emphasized that patients wish to reciprocate back to technology by providing it with data related to their treatment, medications, diagnoses etc. In this way they help other patients who are going or will go through a similar disease.

Our findings also indicate an emerging form of patient not only as a mere user of a health app but also as an active participant in its development and as a designer herself – the patient entrepreneur. This is the case of patients, or sometimes carers and patient organisations, who motivated by their health condition and by the expertise they have developed overtime managing it, make a decision to proceed to the development of an app that meets their specific needs.

One perhaps of the most interesting ways in which patients become activated in online platforms is by sharing their experiences of healthcare delivery and clinical encounters. Online patient stories can be shared and accessed by a number of other interested users, be that patients, carers, doctors or nurses. By being made online they become public, sharable and social having broader effects, often unintended, on other people. A representative of Patient Opinion, an online platform intended for enabling patients to share online feedback on the basis of their experience, described the sharing of patients' stories as a way of healing the self. Healing means here an unintended consequence that emerges from patients' awareness that their story matters to other people rather than herself. Further, because in many cases patients' stories have some form of intentionality in the sense that they are directed towards a specific service, healthcare organisation, clinic or doctor they are likely to trigger a response that addresses a problem that is reported in a patient's story. Patients' stories may also play a pedagogic role in healthcare as they constitute a knowledge base out of which doctors learn about patients' experiences, about areas that are considered as problematic and the reasons they may be considered as such and think about potential actions or best practices.

5   Concluding remarks

Our findings indicate that developments in digital health technology, such as health apps and online patient platforms, intended for patients' management of their health give rise to a phenomenon of digital patient activism. Digital patient activism refers to the possibilities digital health technology provides for patients to get involved in the co-production of health knowledge, creating in this way benefits not only for other patients (Barrett et al., 2016) but also for healthcare providers, for designers and for medical trainees. Our study thus adds to Radin's work (2006) that sees health activism as an unintended and bottom-up initiative that is taken by individual patients and not as an institutionalised initiative.

We refer to patients' co-production of knowledge because the type of knowledge patients produce cannot happen independently of a sociotechnical context within which they find themselves. This context is both discursive and material, including a political rhetoric that gives meaning to patient activation; digital health technology that constitutes the main facilitator of patients' activism; other patients and carers that listen to, seek for or provide help, administrators that approve and moderate patients' content; designers that create the technology and a range of social enterprises and brokers that mediate this production process. Production of health knowledge is thus an outcome of the interplay of a number of players in the field and cannot occur outside and independently of them; this is why we name it co-production.

Our study suggests that there are at least four modes in which patient activism becomes manifest. The first is through the production of data for clinical purposes. This refers to patients that provide health data as they use digital technology - e.g. health apps – to manage their condition or to patients who have been cured and wish to reciprocate by providing information about their diagnosis and/or treatment to other patients who may be going through the same experience. The second is through patients' involvement in the design of health apps. This refers to patients who decide to become entrepreneurial by designing health technologies that will be of use either to them as patients or to family members and/or friends who have been diagnosed with a condition, usually chronic. The third is through the use of health IT channels (e.g. patient platforms) where patients share stories and narratives of their experience of health. Sharing stories with peers has a therapeutic effect both for the author of the narrative as well as the reader of it. The fourth is in online patient platforms where patients provide feedback to healthcare organisations and professionals (nurses, doctors etc.) about their experience of healthcare delivery. In doing so, they create a knowledge base that is being used for educating healthcare professionals in the future. Digital patient activism is thus about the co-production of health knowledge (via apps or platforms) that meets clinical research purposes; technological ends; therapeutic needs and training objectives. This epistemic knowledge generates value to the broader community (Barrett et al., 2016); value that is not necessarily of monetary nature (Lupton, 2014) but is about the caring of the other achieved through the care of the self.

Findings suggest however that not all patients can become activists. Some patients are excluded from this possibility due to poor literacy skills, low socioeconomic status, demographic reasons (e.g. the elderly) and also due to medical conditions that deprive patients of any capacity to become activated such as patients with dementia. Digital patient activism is not an inherent ability patients have, as recent health policy suggests, but is conditional and performative. We would also like to emphasize that digital patient activism draws on conditions that are problematic and require further enquiry. We refer here mostly to the assumption that underpins recent policy that information is 'health service in its

own right' (Department of Health, 2012 p. 50) and to the inextricable connection between patient activism and a neo-liberal discourse according to which individuals (in our case patients) are responsible for making choices, previously taken by the state or the professionals. The ethos of self-care seems to be inextricably linked to the ethos of the new liberal self, despite the positive ramifications it may have.

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