Need for patient-developed concepts of empowerment to rectify epistemic injustice and advance person-centred care

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ABSTRACT

The dominant discourse in chronic disease management centres on the ideal of person-centred healthcare, with an empowered patient taking an active role in decision-making with their healthcare provider. Despite these encouraging developments toward healthcare democracy, many person-centred conceptions of healthcare and programming continue to focus on the healthcare institution's perspective and priorities. In these debates, the patient's voice has largely been absent. This article takes the example of patient empowerment to show how the concept has been influenced by a variety of competing and shifting influences that have led to conceptualisations and programming designed for the patient, but developed without the patient. The framework of epistemic injustice is proposed to unravel the complexity of these omissions. The concept can be defined as a wrong done to someone specifically in their capacity as a knower. It occurs when a person is ignored or not believed due to a prejudice of some kind. It has been applied to healthcare in order to better understand barriers for patient participation and will be used to better understand the problems with current empowerment definitions and implementation strategies. The article will end by proposing some methodologies to facilitate patient-developed concepts of empowerment.

INTRODUCTION

This article aims to unravel the problems with current empowerment conceptions and programming in order to propose new methodologies facilitating greater patient involvement. At the current time, there is no consensus on a definition of patient empowerment and much conceptual confusion. The concept has been and continues to be influenced by a variety of competing interests and visions of the patient's role. The genesis of the overall empowerment concept can be traced to the period following World War II and leading up to the civil rights movements in the 1960s and 1970s, as part of wider political and social movements reflecting society's call for greater autonomy and self-determination.[1] During this time, there were important social movements that helped incorporate the patient into these debates. The first influence was the birth of bioethics, which led to advocacy for the right to informed consent and a focus on patient autonomy. A second influence was public health discussions on a wider scale in the 1970s, influenced by international charters such as the Alma Alta Declaration, which sought to put health promotion on the global agenda as a human right.[2] Patient's rights, and in particular advocacy for patient involvement in healthcare decision-making, have been prioritised in these debates.

The concept of patient empowerment grew out of these diverse and competing interests within and outside healthcare. Barbara Solomon's 1976 work *Black Empowerment: Social Work in Oppressed Communities*[3] first coined the term 'empowerment' as a process to reduce the powerlessness of stigmatised groups. Powerlessness was understood as more complicated than just lacking power, as people are also prevented from acting by self-perceptions about their resources. Solomon tasked support providers with helping people overcome felt and enacted powerlessness, an idea seen in patient empowerment programming today through methodologies such as therapeutic patient education.

These ideas about empowerment were also given a collective dimension through Paolo Freire's work *Pedagogy of the Oppressed*.[4] For Freire, *critical consciousness* is a group process in which groups identify common roots of their powerlessness in order to overcome oppression. In order to work together, individuals must first become aware of themselves as subjects in a process he calls *conscientisation*. Freire's work has been highly influential in how empowerment is implemented. Empowerment programming has centred on developing this *conscientisation*, in particular by helping individuals to develop the skills, understandings and resources to be empowered. The process is often viewed as linear and when it is achieved, a result.[5]

However, the concept of patient empowerment has shifted past these first conceptualisations into new forms due to competing intellectual and political influences specific to healthcare. The first was advocacy coming from nurses and other paramedical professionals to reduce hospital asymmetries in the 1970s. As professionals claimed their right to participate in medical decision-making along with doctors, they demanded new programmes to facilitate greater patient interaction to account for their special skill set with patients.[6] Patient empowerment programming, and in particular programmes like therapeutic patient education, has been one of their outcomes.

Another important influence was the rise of powerful political movements such as New Right politics in the USA and the UK. These ideologies influenced what is often viewed as citizen movements, such as the advocacy for 'self-help' healthcare in the 1980s.[7] Patient responsibility has been encouraged in these movements in order to improve healthcare outcomes and reduce healthcare expenditures. Although these ideas have helped patients to be seen as *active* rather than *passive*, they have also led to high expectations of the patient. Because of this, patient empowerment programming, in particular therapeutic patient education, has focused on educating patients to ensure treatment adherence.

This article will now proceed by introducing the current definitions and programming stemming from these diverse influences. It will then outline the philosophical concept of epistemic injustice to show why exclusion of the patient's perspective in these debates is a problem both for healthcare democracy and in terms of efficiency and efficacy of healthcare plans. It will end by proposing several methodologies to encourage a more inclusive development of the patient empowerment concept.

Patient empowerment definitions

The shifting and competing priorities surrounding empowerment have led to a multitude of conceptualisations and programming in healthcare institutions. In addition, depending on its focus on the individual patient level, the doctor–patient relationship, the healthcare system or the society level, patient empowerment leads to different interpretations, such as a theory, a process, an intervention, an outcome[8] and to different policies and programming priorities.[9] These varying definitions of responsibility have led to numerous difficulties for the design and implementation of patient empowerment on the ground, but also to conceptual confusion for healthcare institutions, policymakers, patient groups, patients and their caregivers.

Among popular definitions are:

1. An educational process designed to help patients develop the knowledge, skills, attitudes and degree of self-awareness necessary to effectively assume responsibility for their health-related decisions.[10]
2. A redistribution of power between patients and physicians. Empowered patients attempt to take charge of their health and their interactions with healthcare professionals.[11]
3. A process that helps people gain control over their own lives and increases their capacity to act on issues that they themselves define as important.[12]

These three definitions reflect the varying influences in the overall empowerment movement and those linked specifically to healthcare. The first definition, focused on the individual patient level, aims to facilitate individual responsibility for health decisions. It conceives of empowerment as a linear educational process, which means there will be an educator (the healthcare provider) who decides what *knowledge, skills, attitudes and degree of self-awareness* are to be achieved, and the person to be educated (the patient). This concept is a mix of Freire's concept of *conscientisation* with the promotion of patient responsibility. While the healthcare provider's role is evident, the patient's contribution to this process remains unclear.

The second definition is orientated toward the doctor–patient relationship. While this definition takes into focus the collective empowerment movement advocated by Freire, seeing it as part of a general societal trend involving the redistribution of power, it then goes on to show that empowered patients 'take charge' of their health, advocating individual patient responsibility for healthcare outcomes. The problem with this definition is that it fails to take into consideration that power relations do not necessarily disappear in person-centred models; instead empirical research has shown that power relations have evolved and new relational complexities developed.[13] For instance, patient-centred communication, often emphasised as a means to achieve person-centred care, may empower the patient and help the healthcare provider with a diagnosis; however, it does not liberate these actors from the increasingly complex and subtle manner in which medical decision-making occurs.[14]

The third definition, proposed by a patient's group, is focused on both the patient in healthcare and as a person in society. The focus here is for patients to gain control of their lives and not just in their medical care. This process is aligned with Solomon's view of helping patients to overcome their powerlessness. The patient has a clear role in this process (to define what is important to them). However, in this definition, we do not know how much control patients realistically have. This concept is therefore still too focused on the individual patient level and may be missing the critical role of the facilitating environment in the realistic exercise of patients' choices.

Patient empowerment programming

Patient empowerment has also been expressed in various ways and means in healthcare institutions. For instance, one increasingly popular way to measure patient empowerment is through the Patient Activation Measure (PAM) which assesses the individuals' knowledge, skills and confidence to manage their health through a series of stages of activation. The tool defends the idea that activated patients who believe that they have important roles to play in alliance with their healthcare provider will learn how to 'manage' their disease and implement better health behaviours. While originally conceived with input from experts in chronic disease,[15] it is primarily a tool for healthcare providers to help plan discussions with their patients. With this methodology, the healthcare provider's role is evident (following Solomon, to help patients overcome their powerlessness); however, individual patient involvement into the evaluations of the various stages of activation remains unclear: it will likely consist of implementing a predetermined set of strategies designed for them by their healthcare providers.

Another popular implementation methodology is therapeutic patient education programmes, designed to train patients about their disease. By being initiated and put into place in the institutional cadre, they have been largely designed by healthcare institutions. In recent years, patient experts and patient organisations have increasingly become involved. While they have helped integrate some patient perspectives into healthcare planning, they have not radically changed their design.[16] The first priority in these programmes is to encourage patients' rights to participate actively in their healthcare and to be informed about their disease and their treatment. The second priority, however, is for programming that leads to better healthcare outcomes, in particular by encouraging patients to adhere to their treatment regimes.[17] Because of this second objective, Skelton claims that these programmes are a form of 'disguised paternalism'.[18] In other words, healthcare institutions are claiming ethical talking points in the promotion of such programmes (the patient's right to participate, to be informed, to know about their disease), while also promoting the healthcare institution's priorities (adherence). Not only is this not transparent for the patient, but it does not give the individual patient a voice into design or evaluations of the programmes built for them.

What these discussions of patient empowerment bring to us is a problem. The individual patient's voice has been silenced, discounted or ignored into the conceptualisation of patient empowerment and in its formulation on the ground. This is a question of epistemic justice.

EPISTEMIC INJUSTICE IN HEALTHCARE

An essential feature of personhood is the ability to participate in the spread of knowledge and to be believed by others. In daily life, people incorporate a variety of roles in society, including as sources of information and/or as informants. A problem occurs when a person seeking to convey knowledge to others, or seeking to make sense of their experience in the social world, encounters a prejudice, causing their testimony to be ignored or not believed. Miranda Fricker has proposed the concept of epistemic injustice to highlight this difficulty. She defines this as a wrong done to someone specifically in their capacity as a knower.[19] A growing literature has applied the concept to healthcare to better understand barriers for patients in healthcare. The concept has helped clarify, for instance, problems of patient participation in the consultation, such as when a patient's testimony about their symptoms is not taken seriously by their healthcare provider because of their status as a patient.[20] It has also been used to highlight how medical narratives dominate patient experience, leading to frustration and confusion for patients.[21] In this article, we will discuss how healthcare policies and theoretical conceptions may perpetuate epistemic injustice.[22]

Fricker has distinguished two types of epistemic injustice: *testimonial injustice* and *hermeneutical injustice*. The first type of injustice occurs when prejudice causes the person to give a deflated level of credibility to the speaker's words. An example is patient profiling: when a healthcare provider makes assumptions about the credibility of the patient's speech based on their appearance, ethnicity or gender, this can lead to ignoring or disbelieving what the patient tells them. Thus, while profiling remains an important tool used by healthcare providers in their everyday practice, it can also lead to exclusion of the patient's epistemic contribution[23] during the consultation.

Fricker says that testimonial injustice can also happen in different temporalities: the person's viewpoint for instance may not be taken into account afterwards or pre-emptively. Thus, it can also be expressed through *silence*. An example of this is when the patient decides not to give important information to their physician because of the fear of not being taken seriously.[24] These examples show that testimonial injustice can have an impact on the efficacy and efficiency of the healthcare plan, in particular when the information disbelieved includes clues that may help the healthcare provider in their diagnosis or treatment.

Fricker also argues that socially excluded groups may suffer from a rupture between understanding and their experience. This makes it difficult to convey their experience to others or to make sense of it. This leads to the second type of epistemic injustice. She defines hermeneutical injustice as, '*the injustice of having some significant area of one's social experience obscured from collective understanding owing to hermeneutical marginalization*'.[19] An example of this is sexual harassment: before its recognition by society, persons experiencing this problem had difficulty both in conveying their experience and being believed by others, as the concept did not (yet) exist. In healthcare, hermeneutical injustice has helped understand how patients may feel when medical discourses do not reflect their illness experience, leading to difficulties in understanding or relating their illness to others. This type of injustice has been highlighted in particular for controversial conditions such as chronic fatigue syndrome.[25]

For our discussion, we can see that patients have subject to testimonial injustice by not being solicited into the empowerment concepts and programming designed for them. This exclusion of the patient's voice is not necessarily intentional, as the qualitative nature of individual patient experience makes it difficult to feed into quantitative healthcare evaluations, including clinical evaluations and guidelines.[26] However, qualitative accounts are necessary to move the concept forward from the patient's perspective. As Roberts has stated, '*the lack of theoretical guidance and simplification of the* (empowerment) *concept call for the need for more qualitative research. Such research could elicit individuals' own definitions of patient empowerment, which would, in turn facilitate the development of better theoretical models of the concept*.'[11] For patient empowerment to truly be person centred, patients will need to at least be part of the discussion. For now, their views have been largely sidelined by prioritising institutional goals. For instance, PAM is a quantitative tool to be used across a variety of settings and specialities to help healthcare providers understand the patient's progress. It does not allow individual patients to define the stages of their activation nor what self-management means to them as individuals. Similarly, unless therapeutic patient education programming can adjust its content and goals to take into consideration each patient's specificities, it will not necessarily reflect what the individual wants to learn or achieve.

Epistemic injustice literature shows that marginalised groups can be silenced in dominant discourses but still have their own framework to understand or express their social experiences.[27] Therefore, we cannot necessarily say that patients lack understanding of how they wish to be empowered, but rather that current frameworks designed for them have not necessarily taken into account their perspective. This may be a case for hermeneutical injustice, and it may help explain why patient empowerment programming is for the moment only partially successful. In the case of PAM, patients may be confused, misunderstand or be unwilling to participate with their healthcare providers, as the tool may not reflect their ideas of what it means to be empowered. In the case of therapeutic patient education, while the methodology has generally been shown to increase patient adherence,[28] approximately 50% of patients still do not take medication as prescribed.[29] Patients choose to adhere (or not to adhere) to their medication for a variety of reasons,[30] suggesting that this type of programming could benefit from patient contributions to increase its impact both from the healthcare provider and the patient's perspective.

It will also be necessary to put up for discussion the assumptions we have about the patient in current person-centred models. Many of these frameworks presume that the patient has a high level of capacity in reasoning and verbal expression; however, not all persons will have all of these capacities, nor will they be necessarily willing or able to use them in the real world of the consultation.[31] Making these kinds of assumptions in models of person-centred care can also lead to further epistemic injustices, in particular as those communication models which do not fit the expected discourse may be discounted or ignored.

Finally, patient empowerment conceptualisations assume that patients are disempowered. Is it really for healthcare institutions to say that patients are disempowered? While we may be claiming that patients that are disempowered have the right to become empowered, we are making a judgment on their state of being and the desirable qualities that we wish for them to cultivate. As Cribb and Gewirtz have argued, we need to pay attention to the risk of 'enforced empowerment' in which persons are given responsibility for things for which they do not necessarily wish to be responsible.[32] Patients may also suffer from burn-out due to these new responsibilities; thus we should be careful about what new tasks we are giving to patients. Furthermore, if patient empowerment is 'desirable', we cannot presume that it is desirable for everyone. Patients vary in the extent to which they wish to participate actively in decision-making and goal setting,[33] and many patients—at least at some point in the healthcare relationship—may also not desire to be empowered at all.

We therefore cannot presume for patients either what it means to be empowered, or how and when they will be empowered. This shows that it is necessary to solicit a more holistic patient perspective in order to better understand how to conceptualise and implement patient empowerment in person-centred care.

PATIENT-DEVELOPED CONCEPTIONS OF EMPOWERMENT

The aim of revealing these epistemic injustices is to find possible solutions. Fricker has suggested that we can rectify epistemic injustices through *critical self-awareness*.[19] The ultimate end of this type of correction is both *justice* (from the ethical perspective) and *truth* (from the epistemic view) to the person wronged in their capacity as a knower. Healthcare providers and healthcare institutions can develop this kind of critical self-awareness in order to better pay attention to and solicit patient contributions. It can notably be used to rethink about who we are inviting to the table in healthcare discussions, including which patients are being solicited. For the moment, so-called expert patients and patient associations are the main representatives of the wider patient population, which does not necessarily represent the capacities and desires of all patients. To rectify this shortcoming, it will be necessary to invest in qualitative and participatory research processes, which will seek to gather, honour and understand the priorities of individual patients. The end goal of such research will be to facilitate better theoretical models of the concept, as well as move toward greater consensus for a person-centred concept of empowerment that can be adopted by a wider group of actors. There are at least two possibilities here: either such research could change the way we view empowerment entirely, or the new concept(s) will be a compromise between institutional and patient needs. However, it will already be a step forward to actively solicit a wider group of patient contributions.

In the meantime, soliciting the individual epistemic contributions of patients can already be done in programmes like therapeutic patient education. For instance, asking the patients their needs and priorities in such a training, how they wish to achieve these and what support they will need from healthcare providers, caregivers, employers and educational facilities, rather than centring the programme design (only) on adherence or healthcare outcomes, will help ensure the training is personalised to their needs and desires to participate. This process can also help healthcare providers better understand the individual social and psychological barriers facing their patients.

In these emerging conceptualisations *with* patients, it will also be important to take into consideration wider social factors affecting patient empowerment, rather than placing the sole responsibility on the patient. Feminist scholars have heavily criticised empowerment's lack of focus on structural conditions. Carr,[5] for example, declaims, '*empowerment seems to exist in a vacuum in that contextual and structural factors are noted but not integrated*.' This understanding of the critical role of the environment has surprisingly not yet been integrated into most patient empowerment conceptualisations and programming (and is only starting to be incorporated into understandings of adherence), even though it represents a considerable barrier to whether or not patients can actually be empowered for their healthcare outcomes.

CONCLUSION

In recent years, we have moved forward with person-centred programming by involving patients in healthcare decision-making, policy development and even in medical education. Despite these evolutions, patients continue to be frustrated with a healthcare model that is centred on them, but which continues to imperfectly reflect their capacities and desires to participate. Their lack of contribution into patient empowerment discourses and programming has led to imperfect methodologies to work with the patient. If we truly wish to move toward person-centred care, it is about time that we solicit the epistemic contributions of patients into the healthcare concepts and programming that is designed for them.

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