

Introduction

What is the nature of trust relations between patients and physicians? Trust is central to relations in which parties are unbalanced in terms of their expertise, ability, and control in a situation (Whyte & Crease, 2010), and the case of physician-patient relationships exemplifies this. At first glance, many assume the physician more expertise, ability, and control than the patient; however, while patients experience both perceived and actual deficits, they also have advantages due to their position, such as access to unique expertise (especially embodied knowledge of their own physical state), power in their choice of the extent to which they follow physician advice or treatment plans, and control over whether they defer to a physician at all. Diversity in perspectives from both physicians and patients is beneficial in terms of objectivity if leveraged well (Longino, 1993), and may also take into account that traditional experts in medical fields otherwise would not have access to; unfortunately, these potential contributions of patients are often ignored, and trust relations consequently suffer.

Overall, the contributions of all parties to medical policy and practice are limited by factors that harm trust in the relationship, decreasing uptake of useful knowledge, and the produced knowledge's significance and usefulness (epistemic merit) (Grasswick, 2010). Informed patients bring useful information and expertise to their relationship with physicians, but are often distrusted. Through understanding the nature of expertise and trust relationships between patients and physicians, we may improve medical policy and practice through encouraging uptake of information from both physicians and patients. This paper will first examine forms of trust in relationships between scientific and “lay” communities, consider how parties in the physician-patient relationship may gain and use expertise, analyze the physician-patient relationship and assumptions within it, and make recommendations for how to improve the epistemic merit of results from this relationship.

Methods

In this paper, I explore varying definitions of trust, relationships, and experiences of them from across the disciplines of social epistemology, scholarship in collaboration, economics, and human factors engineering. I discuss cases of ethical importance involving deception and trust breakdowns, along with research from healthcare and sociology. I also consider the experiences of informed patients, and the responses they have received from physicians. These differing approaches are integrated in a discussion to further illuminate the nature of trust relationships with respect to varying forms and degrees of expertise.

Trust

The consequences of trust relationships between scientific and lay communities is an important and active area of study¹ in *social epistemology*, which considers the social dimensions of knowledge production and transmission. One of the main factors considered is *trust*, defined as willingness, comfort, and confidence in deferring to another about things beyond one's knowledge, power, or control such that they would have the ability to cause harm (Whyte & Crease, 2010, p. 412; Hardwig, 1991). Trust can be defined as *moral*, where the trust is based on factors such as one's perceived character and reputation (Karna & Ko, 2015, p. 265), or *strategic*, which depends upon the rational actor hypothesis, assuming that everyone will act in their own best interest with perfect information (Hardwig, 1991; Rybczynski, 2016). Strategic trust as a complete understanding of trust is incompatible with much of feminist epistemology due to its dependence upon interchangeable, purely rational beings with full, unbiased knowledge (Hardwig, 1991; Code, 1991). *Mistrust* describes cases where trust is not proportional to reliability or other markers of trustworthiness (Wickens, Lee, Liu, & Becker, 2004, p. 424). In *overtrust* (or complacency), the level of trust is higher than appropriate, and in *distrust*, it is lower than appropriate (Wickens, Lee, Liu, & Becker, 2004, pp. 424-425).

It is often rational for lay communities to distrust medical communities, especially given history of mistreatment on individual or broader scales, such as the case of African-American men and the Tuskegee Syphilis study (Grasswick, 2010, p. 390). Even in absence of such history, the lack of information regarding the processes that underpin knowledge creation makes any trust in such knowledge lacking in information or reliability. To avoid such issues, Grasswick proposes that trust instead be "rationally grounded" (Grasswick, 2010). Rationally grounding trust is not equivalent to "good reasons to believe" in strategic trust, but is more similar to Longino's objectivity in that it involves presenting good reason for people of various *social locations* (e.g. members of marginalized groups) to believe the knowledge. As the aims of knowledge producing communities such as medical disciplines include producing knowledge of epistemic merit that is significant and socially relevant (Grasswick, 2010), those communities must take the responsibility for rationally grounding the trust they expect from patients.

Expertise

Physicians are *contributory experts*, as they have specialist tacit knowledge, complete their professional duties competently, and contribute new and useful information to their fields of expertise (Collins & Evans, Rethinking Expertise, 2007).² The designation of expertise notes the

¹ See Hardwig, 1991; Crease, 2004; Grasswick, 2010; Whyte & Crease, 2010, among others.

² There may be some contention over this (Goddiksen, 2014), as contributory expertise is often defined dependent upon contribution that causes progress within a domain, which standard family medical practice may not do as it uses domain information to make progress for individual cases, the details of which are in most cases not communicated back to the discipline.

depth of their ability; the breadth of their expertise is defined by the scope of their field of study or areas of competency. A contributory expert in, for example, gravitational wave physics may have expertise of a similar depth in other related areas of astronomy, but not have the same depth of expertise in quantum mechanics. Similarly, physicians who specialize in neurology likely do not have a similar depth of expertise in endocrinology. For the purposes of this paper, physicians will be assumed to deal with patients only within their specific domain of expertise.

Informed patients may be said to exhibit *target expertise* that allows them to make informed decisions within certain technical contexts (i.e. the context of their care and specific medical state that they have informed themselves on) (Collins, Evans, & Weinel, Expertise revisited, pt. II, 2015, p. 1).³ Their expertise is clearly practically oriented, as the decisions they make are with respect to their own care, not some “esoteric” piece of pure academic theory (Collins, Evans, & Weinel, Expertise revisited, pt. II, 2015, p. 2); however, they would fail to pass the “imitation game” test of linguistic fluency, as they have not been immersed in the environment of those contributory experts and often see no need to “speak the language”.

Though these linguistic barriers decrease the perceived credibility and knowledge of informed patients, it does not mean that their comprehension or ability to apply their knowledge is lacking. Patients with this form of expertise may still indirectly produce contributions and “interact interestingly” (Plaisance & Kennedy, 2014, p. 61) with physicians – the definition of *interactional expertise* Collins & Evans introduced in their 2002 paper on forms of expertise (p. 254). This definition has been retracted (Collins, Evans, & Weinel, Expertise revisited, pt. II, 2015), and for similar cases such as Epstein’s account of AIDS treatment (1995), they note the need for “new and more diverse forms of expertise” (Collins, Evans, & Weinel, Expertise revisited, pt. II, 2015, p. 3) to account for what they exhibit, but do not present additional solutions. Another definition of interactional expertise claims it provides expertise in a language without expertise in practice (Plaisance & Kennedy, 2014); this is clearly not representative of informed patients, who have expertise in practice without significant expertise in language.

Weaker forms of expertise such as ubiquitous primary source knowledge (Collins & Evans, Rethinking Expertise, 2007) are similarly inadequate; the expertise displayed by informed patients goes beyond simple memorization, knowledge, or comprehension. It involves synthesis of many sources (including their own embodied experiences) and application of that expertise to managing their own health day-to-day and on a larger treatment plan scale. It is clear that informed patients have expertise that is not adequately captured within Collins & Evans’ model as it currently stands. Developing a new categorization or taxonomy of expertise is well beyond

³ Note that “*informed patients*” does not refer simply to patients who simply listen to their doctors or conduct cursory research at the popular understanding level, but those who perform significant research and synthesis with the intent of informing their treatment plans. This label is more likely to be applicable to people with ongoing conditions as the stakes and length of time they face such conditions are increased.

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the scope of this paper; however, I have here demonstrated that informed patients do have expertise, even as it has not been appropriately categorized or recognized.

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As previously noted, the physician-patient relationship exhibits asymmetries in terms of knowledge and power; however, these are not one-sided. Patients and physicians have different information and power, and trust must also act in both directions. While non-informed patients typically are complacent with their care, physicians have been shown to routinely distrust and dismiss information from patients, viewing patient self-education as a “burden” on physicians (Ahmad, Hudak, Bercovitz, Hollenberg, & Levinson, 2006). Physicians who demonstrate more positive attitudes are often in the following cases: their patient has found information beyond the physician’s scope of expertise, and the physician is prepared to accept it (as opposed to those who view it as “having their expertise challenged” (Ahmad, Hudak, Bercovitz, Hollenberg, & Levinson, 2006, p. 6)); the patient identifies a gap in the physician’s knowledge and requests a referral elsewhere; or, the patient presents information that the physician is prepared to “explain, synthesize, and contextualize” (Ahmad, Hudak, Bercovitz, Hollenberg, & Levinson, 2006, p. 5) – a role they are better suited for due to their disciplinary training.

Note that these cases are where productive and positive trust relations already exist or the information does not challenge them. Such relations are not heavily dependent upon trust as the *principle of testimony*: “If A knows that B knows p, then A knows p” (Hardwig, 1991, p. 698), does not apply; physicians neither confirm nor contradict the information but accept that the patient holds such information uncritically. The latter synthesis (Ahmad, Hudak, Bercovitz, Hollenberg, & Levinson, 2006, p. 5) is the closest to engaging with testimonial information, involving physician expertise in providing additional support for patients prepared to engage critically with the information under review.

Unfortunately, though this task can be very important in ensuring patients have accurate and relevant information, physicians are often highly resistant to interpreting this information, and instead employ strategies to avoid such discussions, such as charging higher rates, sending the patient to a more expensive specialist, or “firing” the patient – concluding the visit early and marking them as overly demanding (Ahmad, Hudak, Bercovitz, Hollenberg, & Levinson, 2006, pp. 6-7). Patients who did mention their research “perceived a risk” to their action (Hay, et al., 2008, p. 580), showing clear issues with the patient’s perception of their physician’s trust and openness to criticism in both circumstances. Additionally, though pain levels for chronically ill patients were positively correlated with information seeking, they were negatively correlated with discussing such information (Hay, et al., 2008, p. 580). A potential explanation, consistent with the impact of “stakes” in trust decisions could be that higher the risk, the more likely patients will refuse to trust only the doctor and instead seek out other sources to corroborate their claims independently.

It is thus not surprising that many patients do not trust their physicians to take their concerns into account, and thus do not bring up their concerns in appointments. One study found about 32% of patients who did research but chose not to mention it did so because they “did not want to challenge [their] physician” (Hay, et al., 2008, p. 4). It is important to be respectful in trust relationships, but this appears not to be a matter of respect but fear of aforementioned consequences where physicians felt “challenged”. This shows a failure to have *open forums for criticism* (open and available means to criticize ideas, not those who hold them) as Longino recommends for more objective knowledge production processes (Subjects, Power, and Knowledge, 1993, p. 112). Some doctors specifically advocate against this, reinforcing the “superiority” of their expertise as necessary to the relationship and its products, claiming: “Part of the therapeutic relationship is the trust and the belief that the doctor will make you better. You don’t have that, you have lost a great portion of your therapy” (Ahmad, Hudak, Bercovitz, Hollenberg, & Levinson, 2006, p. 4).

Assessing Expertise and Trustworthiness

An issue revealed by this quote is the persistent assumption that physicians are the only ones with useful expertise in the physician-patient relationship, and thus the only ones who can and will “make [the patient] better” (Ahmad, Hudak, Bercovitz, Hollenberg, & Levinson, 2006, p. 4). There are a few other assumptions that this depends upon, all centered around the levels of knowledge and expertise each party has and is perceived to have.

First, there is the assumption that the only means of acquiring expertise is through formal disciplinary education, with completion denoted by credentials such as certificates, uniforms, and the designation MD. Expertise is not limited to what credentialed experts in medical fields display; unique embodied and tacit knowledge held by patients is incredibly valuable in addition to the form of “contributory expertise” medical experts have, which is often viewed as the pinnacle of expertise (Collins & Evans, *Rethinking Expertise*, 2007).⁴ Though immersion is certainly a strong means of gaining expertise (Collins & Evans, *Rethinking Expertise*, 2007), it is by no means the only way. The abundance of research on internet-based learning in terms of both online courses and democratization of open information furthers this point. Patients informed in this way have been shown to gain and apply important and relevant information to their own health decisions (Ahmad, Hudak, Bercovitz, Hollenberg, & Levinson, 2006; Hay, et al., 2008), and in the cases of disability and AIDS activists, have used such expertise to cause large-scale changes in policy (Dolmage, 2016; Epstein, 1995). Though the expertise that these communities may employ is different in origin than traditional medical professionals hold, it is still practically useful and worthy of recognition.

⁴ There exists much more diversity in forms of expertise as mentioned above and in Collins & Evans, *Rethinking Expertise*, 2007; Whyte & Crease, 2010; Goddixsen, 2014; Plaisance & Kennedy, 2014; and Collins, Evans, & Weinel, *Expertise revisited*, pt. II, 2015.

Another point that has not been significantly challenged is that of the type of information that may contribute to expertise. Though Collins & Evans do explore tacit knowledge and in their “periodic table of expertises” list specialist expertises as types of tacit knowledge (Collins & Evans, *Rethinking Expertise*, 2007, p. 14), tacit knowledge is often not as central to applications of their framework as the depth of expertise derived from “book learning” as in traditional disciplinary education (Reyes-Galindo & Duarte, 2014). Informed patients who are aware of their own embodied experiences and seek to understand them at a level beyond mere perception gain *embodied* information key to their form of expertise. Such information is in fact unique to those who experience certain conditions and their effects, and can be incredibly important to understanding how certain treatments and conditions affect life for such patients.

The “paternalistic” argument from authority, where physicians are not prepared to cede authority and continue to assume they know best for the patient regardless of the domain of the patient’s concern or depth of their expertise (Ahmad, Hudak, Bercovitz, Hollenberg, & Levinson, 2006, p. 6), is especially problematic, and is amplified in cases where the patient occupies other marginalized social locations that further damage their credibility. It is assumed that physicians, no matter their specialization, will always have greater *referred expertise* from “nearby” areas of expertise and their general education in the domain (Collins & Evans, *Rethinking Expertise*, 2007, p. 15) than informed patients could ever gain from their own studies. Instead, patients’ greater motivation to seek out, understand, and connect information from a certain specialized field with their own experience often results in patients gaining greater expertise in terms of both recency and depth than more generalist physicians (Ahmad, Hudak, Bercovitz, Hollenberg, & Levinson, 2006). It is clear that this argument is both ineffective and undermines tempered equality of authority and the patient-physician relationship.

Conclusion

Overall, it is clear that trust in the relationship between physicians and informed patients is not conducive to uptake of information and reduces the usefulness and epistemic merit of information produced from all areas. It is known that satisfaction increases for both parties when patients discuss their research with physicians in open and trusting manners (Ahmad, Hudak, Bercovitz, Hollenberg, & Levinson, 2006; Hay, et al., 2008), but both parties are unlikely to initiate such discussions due to the factors outlined above. Further projects should include practically-oriented recommendations regarding how to improve the trust relationship from both sides towards improving patient satisfaction and uptake of well-created treatment plans, and an expansion of conceptions of expertise to include the case of informed patients.

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