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Do your patients trust you?: a sociological understanding of the implications of patient mistrust in healthcare professionals

Samantha B Meyer, Flinders University

Associate Professor Paul R Ward, Flinders University

Abstract

The trust that patients invest in healthcare professionals and their advice has been shown to facilitate positive clinical outcomes, although there is evidence that patient trust in expertise, including healthcare professionals, has been declining over the years. Questions about whether or not to trust healthcare professionals have been raised recently in international media by Australian pop icon Kylie Minogue, who spoke of her alleged initial misdiagnosis with breast cancer and went on to tell women that they should 'follow their intuition' rather than placing unquestioning trust in doctors or medical advice. Given the power of the media in shaping public opinion, there is a potential for such stories to further impact on the already potentially friable doctor-patient relationships, with questions of trust taking centre-stage. Therefore, an understanding of the nature of trust, in addition to the reasons for the decline in patient trust, is exceedingly important for health professionals. This paper presents an overview of social theories of trust that provide a lens through which we can analyse the development of mistrust in healthcare, and identifies ways in which healthcare professionals may aim to facilitate and sustain patient trust.

Introduction

"I was misdiagnosed initially. So my message to all of you, and to everyone at home is, because someone is in a white coat and using big … medical instruments, doesn't necessarily mean they're right. And the amount of stories that I have heard of women going in for diagnosis, being told 'don't you worry about at thing, it's fine'… yeah so I guess you know, you follow your intuition." (Kylie Minogue, on the Ellen Degeneres Show)

The above quote was taken from an American talk show (The Ellen Degeneres Show, April 8, 2008). Ellen interviewed celebrity icon Kylie Minogue regarding her breast cancer misdiagnosis. Kylie appeared on Ellen in April of 2008 and shared her experience, giving the audience advice to 'follow their intuition' rather than making the assumption that their physician is always providing the right medical information. This 'trust in intuition' may be at odds with 'trust in medical advice' within the world of evidence-based medicine, and speaks to the difference between 'experiential/lay knowledge' and 'expert/professional knowledge'.[1]

Her interview was broadcast and reported internationally, making headline news in International newspapers. It is difficult to determine the impact of Kylie's statements regarding her alleged initial misdiagnosis however, in May of 2005 when news of her subsequent diagnosis was announced, there was a dramatic increase in mammogram bookings in Australia. In the two weeks following the publicity of her diagnosis, there was a 40% increase in average weekly screenings in four Australian states.[2-3] This finding was similar to that of the influence of publicity surrounding Nancy Reagan's diagnosis with breast cancer in 1987. The American Center for Disease Control found that following the announcement of Reagan's diagnosis, there was an increase of 12 percent in screening mammography use in Long Island, United States.[4]

Health information is transmitted by a variety of sources.[5] It is provided by not only health professionals, but by sources of information outside of the health system; family members, peers, educational sources,[6] *as well as by influential media sources and celebrities*. The increase in weekly screenings following publicity surrounding Kylie's breast cancer diagnosis in 2005 supports the argument that the "utilization of health services is generally subsequent to the consumption of information" (p.1454);[6] often regardless of whether it is from potentially unreliable sources.

In view of Kylie Minogue's urge for women to trust their instincts, the key purpose of this paper is to outline some ways of conceptualising trust and then provide some domains on which trusting relationships may be built and sustained. Firstly, we demonstrate the importance of patient trust in both

the medical system and their representatives (GPs, nurses etc). Secondly, we provide a broad overview of some social theories of trust that provide a lens through which we can analyse the development and sources of mistrust in healthcare. Finally, we identify some ways in which healthcare professionals may aim to encourage and facilitate patient trust. Whilst the example relating to Kylie Minogue is about cancer, this paper can be used to understand trust in medicine, medical advice and the medical system more generally.

Currently, there is no evidence suggesting that Kylie's comments have had an effect on patient 'trust'; however, trust literature suggests that patient mistrust often stems from media accounts that fuel lay perceptions of professional fallibility and diagnostic uncertainties (i.e. misdiagnosis).[7-8] This literature, along with our knowledge of the impact that Kylie's publicity in 2005 had on patient behaviour, form the basis for our suggestion that the publicity surrounding Kylie's alleged 'misdiagnosis' may perhaps have an affect on patient trust.

Why does it matter if patients have trust in their physicians and the healthcare system?

There is an escalating wealth of literature on trust in healthcare, reflecting the growing awareness in both research and policy communities.[9-10] Patient trust in healthcare is being challenged by societal changes that have lead to increased patient autonomy and access to medical information (including via potentially unreliable sources).[11] Additionally, while some alternative sources of information are reliable, there is potential for poor interpretation of such information without consultation with medical professionals. As noted above, media representations of alleged medical errors often fuel perceptions of professional fallibility and diagnostic uncertainty, encouraging lay people to question the validity of medical and scientific knowledge and potentially the 'trustworthiness' of both medical practitioners and the system in which their knowledge is based.[12] This often results in individuals taking control of their health, either through the rejection of certain aspects of technology (for example, the growth of alternative and complementary medicine) or through taking matters into their own hands (for example, self care via available information systems).[13] While taking matters into their own hands (seeking out health information) can be a form of lay empowerment resulting in individuals and communities making informed decisions about their health,[14] the legitimacy of *some* of these sources is uncertain. For example, it has been suggested that some complementary and alternative medicines are 'less legitimate' than conventional medicine and are in need of more evidence based testing.[15]

In a recent research project on how women with breast cancer want their doctors to communicate with them, researchers found that women with breast cancer did not think about their doctors according to

whether they 'communicated well', but rather, they were concerned with whether or not they could trust their doctors.[16]

Trust between a patient and physician can encourage a patient's willingness to seek care,[17] encourage patients to submit to examination and treatment,[18] enhance the likelihood of return for follow-up care,[19] increase patient receptiveness to health promotion counseling, facilitate health information exchange, enhance the quality of interaction between patients and physicians, facilitate disclosure by patients, enable providers to encourage necessary behavioural changes, and may grant patients more autonomy in decision making about treatments.[20] In an age where we are seeing increased cultural diversity and potential language barriers, trust is crucial for patients struggling to accept diagnoses and to follow complex treatment plans.[11] Patients with trust are more likely to be satisfied with the medical care they received and to have positive clinical outcomes.[19]

In addition to patient trust being important for the quality of their care, it is also important for physicians and the medical system as a whole. For example, as mentioned above, for the 2 weeks following the publicity surrounding Kylie's initial diagnosis, the average weekly screening in four Australian states went up 40% and the 'Kylie effect' was expected to have a significant effect on reducing breast cancer deaths due to increased referrals and breast cancer awareness.[2] However, this increase in referrals yielded no more malignant diagnosis that prior to the publicity.[3] Twine (2006) argues that media attention such as Kylie's may be detrimental in terms of an increase in investigative exposure to mammographic radiation, as well as increasing anxiety stemming from fear and invasive examinations.[3] While potentially unnecessary mammograms may be harmful to the patients themselves, they also place unnecessary strain on you as a doctor, as well as additional demands on limited healthcare resources.

What can social theory add to our understanding of patient trust?

Trust can be biologically or culturally institutionalized, but it can also develop as a result of social interaction.[6] Social theory is beneficial in that it can help us to view the social interactions in healthcare that develop, sustain or damage trust. Social theory outlines two forms of trust that are important for understanding (mis)trust in healthcare; institutional [21] and interpersonal [22]. Institutional trust is that which is placed in one or more social systems (e.g. economic, legal, medical, political systems) or institutions (e.g. Royal College of General Practitioners, hospitals, general practices etc). Interpersonal trust is negotiated between individuals; for example, trust between patient and physician. One of the central issues in the sociology of trust is the strength and direction of the relationship between interpersonal and

institutional trust and of relevance to this journal is the question – how can a practitioner develop interpersonal trust with a patient?

This paper specifically discusses the trust theories of Anthony Giddens and Niklas Luhmann because both have been consistently cited in the majority of literature on trust in healthcare [20-23-29]. In addition, a combination of Giddens' and Luhmann's theories can help to provide insight into the complexity of the relationships that affect patient trust in both the medical system and individual practitioners. While both look at individual and institutional trust, they present conflicting views about how (mis)trust develops. This contradiction provides opportunity for analysis into the complexity of (mis)trusting relationships in healthcare; together, their theories outline a web of relationships that contribute to (mis)trust in both individual physicians and the medical system as a whole. This paper provides a brief overview of the theories of Giddens and Luhmann (readers interested in reading a more in-depth critical review of social theories of trust and their application in health research should see Meyer et al. (2008)[30]).

Luhmann argues that trust in the institution (the medical system) is necessary before an individual (the patient) can have trust in the system's representative (the physician); that trust in the medical system is projected onto the representative or healthcare professional providing diagnosis and treatment. If a patient lacks trust in the medical system, in theory, they would be unlikely to trust the opinion of the physician (the system's representative). However, Luhmann also views society as a variety of social systems that mutually interact with one another.[31] The institutional trust that an individual places in one social system is highly dependent on their trust in other social systems.[32] Using Luhmann's theory, we may argue that an individual's decision to accept and adhere to a healthcare professional's diagnosis and treatment plan is dependent on their *trust in the professional*, which is a reflection of their *trust in the healthcare system and all other systems that it interacts with/is influenced by* (for instance, the economic system, the political system).

Systems that impact the healthcare system may include the media; our trust in the media as a source of information may affect our (mis)trust in the medical system. For instance, news stories regarding health and medicine can cause sudden dramatic changes in consumer behaviour; especially when these new stories revolve around celebrity health.[2] In the case of Kylie's diagnosis, there was a dramatic increase in the number of women screening for breast cancer; an increase in the consumption of medical advice/technology. In light of new information (Kylie's misdiagnosis), we may see different patterns emerge; for example, seeking additional opinions from complementary and alternative therapies. Further research is necessary to determine if the publicity of Kylie's statements (fuelled by the media) had an

effect on women's *perceptions* of the validity of medical practitioners, the medical system and/or diagnosis. Whether or not it affected their 'trust' in the medical system is still in question.

Contradictory to Luhmann, Giddens maintains that interpersonal trust in the systems representative (the physician) is necessary before there is potential for trust in the institution (the medical system). Giddens argues that trust acts as a medium of interaction *between modern society's systems and the representatives of those systems*.[33] The grounds for this interaction are referred to as 'access points'; the meeting ground for what he terms 'faceless' and 'facework' commitments.[34] Facework commitment is dependent on the demeanour of the 'expert' (in health systems, the physician or other health professionals); their level of professionalism, mannerisms, and other aspects of their personality that impact upon our impression and expectation of them. Alternatively, faceless commitment is the perceived legitimacy, technical competence, and the ability of the 'expert system' (the medical system). Giddens argues that trust is sustained through facework commitments [34] - trust in the physician is required in order to have trust in the medical system. The access point is the meeting ground between the physician and the medical system, whereby the physician is seen to represent the medical system. *"Although everyone is aware that the real repository of trust is in the abstract system, rather than the individuals who in specific contexts 'represent' it, access points carry a reminder that it is the flesh-and-blood people (who are potentially fallible) who are its operators"* (p. 54)[34] Using Giddens' theory, we may argue that mistrust in the medical system is representative of society's acknowledgment that it is the physicians, specialists, and healthcare professionals who are potentially fallible.

Kylie's statement that 'because someone is wearing a white coat and using big instruments, doesn't necessarily mean they're right' may strengthen Giddens argument. She is acknowledging that it is the representative of the system that we place trust in; the characteristic 'white coat' worn by the physician is a symbol of their representation of, and affiliation with, the medical system. Various trust research suggests that individuals use 'symbols of trustworthiness' which are significant when estimating the trustworthiness of others.[32-35] The 'white coats' and 'big instruments' Kylie mentions can be understood as these 'symbols'; they represent what patients recongnise as someone with 'expert' or 'professional' medical advice. Giddens suggests that medical professionals are the representatives of the system; that we must place trust in them before we can place trust in the system. Kylie's suggestion that these symbols do necessarily represent sound 'expert' advice may affect the behaviour of healthcare consumers. As mentioned with regards to Luhmann, further research is needed to determine what kind of impact Kylie statements have had on patient behaviour; whether they have made individuals more cautious consumers of healthcare, or actually affected patient 'trust'.

Understanding the complexity of the relationships that affect patient trust is essential to understanding initiatives that can be made to improve trust in healthcare. Both Giddens and Luhmann construct their theories of trust relationships as linear; ignoring the web of interactive relationships that may influence individual trust. In addition, their theories fail to address the role that social factors[i] (such as socioeconomic status, ethnicity, age, gender, education etc) play in an individual's decision to trust. However, when taking both of their theories into consideration, they do provide insight into the multidimensionality of the relationships affecting patient (mis)trust. If trust is understood to be initiated by the physician, the medical system, and/or broader social systems that influence the health system, trust on all levels needs to be addressed when determining how to encourage patient trust. Trust is a multidimensional phenomenon; both trust towards the health system as a whole, and trust towards the healthcare provider in particular, need to be considered when trying to gain a comprehensive understanding of patient (mis)trust.[6]

Encouraging patient trust - what can you do?

As discussed earlier, trust can be understood as a complex web of relationships between individuals and systems. Therefore, initiatives that aim to increase trust levels have to take into account several factors,[6] although many of which are beyond the scope of this paper and are in need of further empirical investigation. Taking this into account, this paper does not claim to offer a universally applicable, all-encompassing understanding of trusting relationships, but rather, it offers empirically and theoretically supported information on methods for potentially encouraging patient trust. Empirical literature around doctor-patient trust has identified certain physician characteristics that have been shown to encourage patient trust: ability [16] (also termed competence [39]), benevolence, integrity, respect, and honesty.[16-40]

Ability or competence

Physicians are agents of social control; they hold medical knowledge that is limits our view of illness to a specific scientific framework that determines whether the body is normal (healthy) or abnormal (sick).[41] While this grants medical professionals an enormous amount of authority and power, they also hold a great deal of responsibility to understand and treat disease while not doing harm.[42] Patient mistrust in a physician's diagnosis and treatment has the potential to be an additional stress to the patient and a further drain of energy; it also has the potential to drive patients to seek other forms of medical information, while missing out on a major source of expert advice (for example, oncologists).[43] Trust in medical practitioners may be increased by demonstrating technical skill such as answering patient questions without hesitation.[16]

For instance, in a study on how people's trust relates to their involvement in medical decisions, the majority of participants that follow their physician's advice think that it is better to rely on the expert judgment of physicians when dealing with medical problems.[44] If this is the case, healthcare professionals need to maintain their patients' trust in the fact that they are indeed receiving 'expert' advice. Reports of professional fallibility may influence patients to question the validity of their physician's advice and potentially, discourage patients from seeking the opinions of healthcare professionals.

Benevolence

Benevolence is the extent to which the person being trusted is believed to want to do good for the person placing trust.[45] In health care, this may apply to medical professionals profiting from private medical care, pharmaceutical incentives, or research agendas, since trust has been conceptualized as "the optimistic acceptance of a vulnerable situation in which the patient believes the healthcare providers will take care of the patient's interests" (p.615).[18] It has also been suggested that patients want private benevolence from their physicians such as tenderness in the face of pain, courage in the face of danger, and comfort in the face of death.[42] While not all patients want this form of support, and not all physicians have the time or energy to provide it, the underlying issue is that patients must feel that diagnosis and treatment options are in their best interest, and not serving the individual interests of physicians or medical bureaucracies.

Integrity, respect, and honesty

Along with expertise and benevolence, trust has an interpersonal element that requires patient-physician communication and respect. One study argues that physicians often communicate poorly to cancer patients so that their diagnosis is 'unnecessarily traumatic', and that cancer patients do not often receive the help they need to understand treatment options.[16] Cancer patient participants in the study wanted options in their treatments and they were concerned with whether their physician respected their status as autonomous individuals. They wanted a relationship where they could not only communicate about emotional issues, but also one where the doctors regarded them as individuals and where the patient and physician shared decision making.[16]

Encouraging patient trust in the medical system

Strong system-level trust in medicine facilitates the formation of interpersonal relationships without extensive knowledge about individual personal characteristics. This is extremely important as there has been a significant increase in the complexity of medical care delivery which often requires patients to form new treatment relationships with providers they do not know.[46-47]

Unfortunately, there have been many developments within healthcare systems in the past two decades that have had substantial negative effects on patient trust in the medical system. For example, medical systems in the United States have experienced reversals in public trust due to highly publicised accusations of medical practices generating incentives to provide excessive services and deriving financial benefit from professional knowledge.[48] The increase of patient mistrust in the medical system is problematic because, if Luhmann is correct, a patient's interpersonal trust in their physician is potentially based on their general feelings towards the medical system.[37]

The cause of the erosion of trust in the medical system is largely due to social developments; [49-50] private healthcare, the growth of pharmaceutical industries, the media sensationalisation of medical errors, as well as many others. As individual practitioners, it is hard to determine what you as an individual may be able to do about this. However, using Giddens theory, we may argue that a patient needs to have trust in the individual physician before they can have trust in the medical system as a whole; that patient trust in you, the practitioner, will develop prior to trust in the medical system. In terms of individual medical practice, trust is morally important,[51] and it is the responsibility of practitioners to encourage trusting relationships with their patients, as well as to provide a trustworthy representation of the medical system. It is interesting to note that patient trust in physicians has been found to be approximately one-quarter higher on average than patient trust in the medical system. However, once interpersonal trust in healthcare providers is lost, it is rarely rebuilt.[52]

Conclusion

This paper provides insight into the importance of patient trust in both the medical system as a whole, and in healthcare professionals individually. Current social theories of trust fail to address the complexity of relationships affecting patient mistrust. We suggest that patient mistrust, in both practitioners and the medical system, is the result of a web of interactive relationships. The media, competing sources of medical information, personal networks (peers, family, and friends), personal experience, as well as many other influences, interactions, and relationships, have the potential to impact patient trust. While individual practitioners may have little control over many of these sources of mistrust, this paper sheds light on ways in which healthcare professionals can encourage trusting relationship with their patients and potentially facilitate positive clinical outcomes.

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[i]The theories of Giddens and Luhmann are also beneficial to health research in that the limitations of their theories present areas for future research.