

The elephant in the room: tackling taboos in women's healthcare

Aarti Kapoor and Merryn McKinnon

Abstract

The medical arena often encounters 'taboo' topics. These appear especially prevalent in women's health conditions, such as menstruation and menopause. Taboos are exacerbated by medical uncertainty, complex jargon, and patients' misunderstanding of the human anatomy — impacting patients' ability to actively participate in a shared decision-making process with their doctor. In this commentary, we look at one example of a medical procedure where taboo topics pose a number of challenges in doctor-patient communication — hysterectomy. We explore whether science communication can address these challenges, as well as contribute and collaborate in other medical scenarios, thereby benefiting both disciplines, and ultimately, patients.

Keywords

Health communication; Public engagement with science and technology; Science communication: theory and models

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Introduction

Health affects us all and often requires us to make decisions about the kind of medical care we wish to receive. A core component in the provision and receipt of an appropriate level of medical care is communication between physicians and patients [Allen, Petrisek and Laliberte, 2001]. However, this communication can be hindered by complex medical terminology which patients may struggle to understand, and this can often get worse if their health condition is considered a 'taboo' topic [Koch-Weser, DeJong and Rudd, 2009; Iavazzo et al., 2015].

A taboo is a subject that is intentionally avoided or not dealt with because it is socially unacceptable or associated with strong feelings of shame and modesty in a

given culture [Traumer, Jacobsen and Laursen, 2019]. In the context of women's¹ health, taboo topics can be summarised as the "three Ms" — menstruation, maternity, and menopause [Grandey, Gabriel and King, 2020, p. 8]. Taking menopause as one example, Rubinstein [2013, p. 182] noted that there is still a "conspiracy of silence" about menopause, which in turn contributes to misinformation and myths. This can manifest in myriad ways, with menopausal women who are significantly affected by menopause symptoms withdrawing partially or fully from the workforce because of their reduced capacity caused by symptoms [Kopenhagen and Guidozi, 2015] and also potentially due to an unwillingness to talk about it with their managers (or vice versa).

An example of a medical procedure in women's health where taboo topics could potentially arise is when women undergo hysterectomy. One of the most common women's health gynaecological procedures performed worldwide, hysterectomy is a complex surgery involving the removal of the uterus [Hammer et al., 2015; Janda et al., 2018]. The procedure is usually considered elective, as it is mostly performed to relieve benign symptoms and improve quality of life [Carlson, Nichols and Schiff, 1993]. A recent study of women who had undergone hysterectomy in Australia found that most women reported their gynaecologist as their most influential source of information about hysterectomy [Janda et al., 2018]. Being elective means that choices need to be made, including the type of hysterectomy — for instance, partial, complete, radical, or one that involves the concurrent removal of the fallopian tubes and ovaries [Russell, 2017]. Patients' preferences regarding any alternative treatments also need to be considered carefully [Carlson, Nichols and Schiff, 1993], which often requires both the doctor and patient to have difficult conversations, and navigate through taboo topics to reach the best choice of treatment. In this commentary, we identify some of the communication challenges that have traditionally arisen during doctor-patient conversations about hysterectomy and women's health in general. We then explore whether there is a role for science communication practices to address these challenges, as well as to contribute and collaborate in the context of other medical scenarios, to bring about a versatile result that will benefit both disciplines, including patients.

Taboo topics in medical shared decision-making

From the patient's point of view, there are two needs that have to be met when visiting their doctor: "the need to know and understand" their medical condition and "the need to feel known and understood" by their doctor [Ong et al., 1995, p. 904]. Yet if a patient presents with a condition that could be considered taboo, these needs may not be met.

Graugaard [2017] points out that discussions between healthcare providers and their patients on taboo topics, such as those relating to sexuality, are generally avoided. The author describes this as the "two-way taboo", where neither healthcare professionals nor patients initiate conversations about patient sexuality, potentially leading to patients tacitly believing "that their problems are rare, irrelevant, and untreatable" [Graugaard, 2017, p. 578]. While the impact of

¹The authors recognise that there may be individuals who have the biological aspects of the female sex, but may not identify as a woman. The literature cited in this paper does not distinguish and refers only to individuals who have both the biological aspects of the female sex, and who identify as a woman. Future studies are needed to explore the communication experience of individuals who undergo hysterectomy within different gender identity contexts.

hysterectomy on sexual function is a major cause of anxiety in women scheduled for hysterectomy, this anxiety is seldom articulated by patients, nor recognised and discussed by clinicians [Mokate, Wright and Mander, 2006]. A U.S. study showed that women contemplating hysterectomy wanted accurate and useful information given at an appropriate time, and health providers who were willing to give them choices and include them in decision-making [Wade et al., 2000]. But ‘taboo’ may get in the way of this.

This lack of conversation between patient and doctor hinders shared decision-making, a process by which an optimal decision may be reached between a physician and a patient who is standing at the crossroads of health [Barry and Edgman-Levitan, 2012]. Shared decision-making is a way to ensure that the patient’s voice is heard as choices are made [Whitney, 2003], yet if the patient and/or the doctor are silenced by a taboo topic, then the patient’s voice may not be heard at all.

In practice, doctor-patient shared decision-making faces several limitations. One of the greatest challenges is the need for genuine engagement of patients in the decision-making process [Barry and Edgman-Levitan, 2012]. This means actively removing the barriers — including barriers arising from taboos — to patient understanding of the nature of the problem, the treatment options and the consequences, and “view[ing] the health care experience through the patient’s eyes”, especially when they are facing “fateful health care decisions” [Barry and Edgman-Levitan, 2012, p. 781].

Uncertainty, risks, and adverse events

Uncertainty in medical care exacerbates difficulties associated with communicating about taboo topics. Medical uncertainty is generally inevitable and considered an innate feature of medicine and medical practice [Kim and Lee, 2018]. Like any surgical procedure, hysterectomy is accompanied by potential medical risks and uncertainty. Available evidence indicates that professional uncertainty about the appropriateness of conducting the hysterectomy procedure is a primary contributor to variations in hysterectomy rates across Western countries [Carlson, Nichols and Schiff, 1993]. Physicians are often reluctant to communicate uncertainties to their patients when making decisions [Katz, 1984]. Simpkin and Schwartzstein [2016] attributed this reluctance to the “culture of medicine” [p. 1713], which focuses on finding the ‘right’ solution.

Hysterectomy risks can present themselves as physical post-operative complications [Ramdhan, Loukas and Tubbs, 2017]. Failure to communicate uncertainty in the procedure or its outcomes could arguably hinder patients’ ability to make informed decisions about hysterectomy and to cope with its potential post-surgical short- and long-term adverse events. For most women who experience surgical menopause following hysterectomy and concurrent oophorectomy (removal of ovaries) for non-cancerous conditions, there is a possibility that hormone replacement therapy (HRT) could be recommended for the management of their menopausal symptoms such as hot flashes [Langenberg, Kjerulff and Stolley, 1997]. This could potentially place the patient within the realms of a taboo health topic [Grandey, Gabriel and King, 2020] for years after surgery. However, doctor-patient communication tends to cease after the immediate post-surgical period of care, ironically, when many of the questions

relating to coping and managing of any post-surgical side-effects and impacts on quality of life may begin to arise.

Hysterectomy may also lead to a number of serious psychological complications post-surgery, some of them strongly linked to taboo topics such as a woman's perception of her sexuality. Post-hysterectomy emotional feelings can include a sense of loss of body parts and fertility; sadness, anger, and depression; a diminished sense of femininity; and anxiety about sexuality, with women between 30 and 40 years old who have no children potentially experiencing more difficulty in adjusting to hysterectomy [National Women's Health Resource Center, 1994]. Despite these wide-ranging post-hysterectomy adverse events, studies spanning over 20 years have consistently shown that women are not adequately informed to cope post-surgery [Scriven and Tucker, 1997; Gercek et al., 2016]. Against this backdrop, recent studies continue to show an ongoing and unmet need for education and effective communication to help empower women during the decision-making process, and in turn enable them to assist other women [Bossick et al., 2018].

Medical jargon and understanding of human anatomy

There is evidence that hysterectomy patients struggle to understand the complex medical terminology involved in their procedure [Mattingly et al., 2017].

Unexplained medical terminology can be a barrier to effective communication in clinical encounters, leading to patient anxiety [Chapple, Champion and May, 1997], which may in turn impact a patient's decision-making, or coping ability. Despite findings from a variety of studies that have shown that patients frequently misunderstand medical terminology [Koch-Weser, DeJong and Rudd, 2009], it is arguably possible that doctors continue to use language their patients do not understand even if they feel they have simplified the terminology they use.

Patient understanding may also be hindered by a lack of understanding of basic human anatomy. Weinman et al. [2009] showed that many patients, and the public in general, are unaware of the location of key body organs, even those in which their medical problem is located. The authors noted that this could have important consequences for doctor-patient communication and healthcare professionals should not assume that patients do not need organ-specific details, even for those organs that are a source of their medical problem. This is also true for women facing hysterectomy. A study in the U.S. found that women are under-informed (and even perhaps misinformed) about female reproductive organs and the consequences of their removal, particularly those who are younger and from minority groups [Harmanli et al., 2014]. The authors of this study concluded that a well-informed patient is better likely to adapt to any post-operative changes after hysterectomy.

Overall, these studies show that an understanding of the human anatomy (i.e., the names and locations of human organ and their functions) is important for patients, as it provides them with an appropriate knowledge and skill foundation. This is important to allow them to make fully informed decisions, appropriately navigate and respond to taboos, and to cope with their medical situation and any post-surgical adverse events. Put another way, an ability to identify, understand and apply scientific information is an important influence on health outcomes — however, science does not operate in a vacuum. As we argue in the following

section, focusing solely on knowledge of scientific information is not enough. Other factors such as a patient's values, beliefs, worldview, and lived experience can also influence their decision-making process.

Exploring the role of science communication in medicine

Science may aim to be objective, yet it deals with intricate issues that cannot always be narrowed down to a set of simple facts [Stirling, 2010]. Platt and Keating [2007] stated that physicians generally placed more relevance on biology or anatomy when managing their patients' illness, while patient beliefs about an illness were influenced by social and behavioural factors. Beliefs, values and biases — of both patients and doctors — also influence responses to medical uncertainty and, subsequently, decision-making [Simpkin and Schwartzstein, 2016]. The challenges of communicating uncertainty and navigating the influence of beliefs, values, and social norms on attitudes and perceptions are familiar to science communication.

Yet, while prior definitions of science *per se* incorporate medicine [Burns, O'Connor and Stocklmayer, 2003], science communication has been described as seeming more focused on delineating a niche for itself, highlighting the points of difference between it and similar fields [Trench and Bucchi, 2010] such as medical or health communication. Perhaps, rather than clinging to a notion of uniqueness, science communication can extend its broad relevance, as well as the transferability of its theoretical underpinnings and practical applications, into other disciplines including the medical field — and possibly even vice versa.

From the previous sections, we have seen that there are several doctor-patient communication challenges relating to hysterectomy. These include the need for doctors to provide relevant and comprehensible information to their patients in order to inform decision-making, actively facilitating a dialogue between them and their patient — including navigating taboo topics — and involving their patient in the decision-making process within the context of uncertainty. All of these challenges in the medical field are also encountered in the practice of science communication. In the following sections, we outline how potentially combining current medical communication approaches with science communication techniques could bring about a versatile result that will benefit both disciplines, and ultimately patients.

Providing relevant and comprehensible information to patients

Good communication techniques are imperative for doctor-patient interactions, as illustrated through the provision of communication training for medical students from the early years of their training [von Fragstein et al., 2008]. The importance of effective doctor-patient communication teaching, assessment, and practice receives continued focus from academics and educators [Cömert et al., 2016]. For instance, in 1999, the Bayer-Fetzer Conference on Physician-Patient Communication in Medical Education developed the Kalamazoo Consensus Statement comprising the essential elements of physician-patient communication, which has been adopted as part of some medical schools' curricula [Joyce, Steenbergh and Scher, 2010].

Yet, poor communication has been acknowledged as one of the most prevalent problems in medicine, and one of the leading causes of preventable deaths in

hospitals [Taran, 2011]. As discussed, often conversations with health professionals necessitate patients' understanding of the body, structure and function of organs, and also the nature of risk of treatment or surgery [National Academies of Sciences, Engineering, and Medicine, 2016]. Medical professionals need to be able to explain many of these things to their patients, without using complex medical jargon. Science communication skills can be used to make communication of complex information accessible. There have also been science communication programs, employing theatre-based improvisation techniques, used to teach communication skills to medical students, which improved subsequent communication in the clinical environment [Fessell et al., 2020].

Facilitating a two-way exchange of information

Medicine has traditionally positioned doctors as the "single, paternalistic authority" [Barry and Edgman-Levitan, 2012, p. 781]. This is similar to the traditional deficit model of science communication, which has the audience as an empty vessel waiting to receive knowledge. Science communication advocates for a move away from this model, in preference of a two-way communication process [Burns, O'Connor and Stocklmayer, 2003]. In the dialogue model, the sender and audience (or receiver) negotiate about meanings and facts [van der Sanden and Meijman, 2008]. Shared decision-making has many similarities with the dialogue model of science communication. Both advocate for a two-way exchange of information between specialist and non-specialist parties and both are a step change from traditional one-way modes of communication.

However, as Barry and Edgman-Levitan [2012] point out, for shared decision-making to be viable, patients "should also receive the emotional support they need to express their values and preferences and be able to ask questions without censure from their clinicians" [p. 781]. A similar concern in science communication was addressed when van der Sanden and Meijman [2008] distinguished the dialogue model as having two different goals. A dialogue about facts has a "functional goal", and a dialogue about concepts and notions (including feelings, emotions and fears) has a "conceptual goal" [van der Sanden and Meijman, 2008, p. 92]. Both these aspects are also needed in doctor-patient communication. The dialogue with a 'conceptual goal' addresses the emotional aspects of a patient's concerns, while the dialogue with a 'functional goal' allows the doctor to then present the patient with the medical facts. Or as Barry and Edgman-Levitan [2012] noted, doctor-patient communication is not only about what the matter *is* with the patient, but also what matters *to* them [emphasis added].

Dealing with uncertainty and risks

Fischhoff and Davis [2014] noted that "(a)ll science has uncertainty" [p. 13664]. Likewise, uncertainty is endemic in medicine, even if it is "suppressed and ignored" [Simpkin and Schwartzstein, 2016, p. 1713]. In communicating medical uncertainties to patients, there are no 'one-size-fits-all' answers. However, research has shown that publics prefer uncertainty to be communicated, even in health-related circumstances [Zehr, 2017]. As we have seen in the case of hysterectomy, openly communicating risk and uncertainty could potentially benefit

both doctors and patients, rather than avoiding its discussion and inadvertently creating a “conspiracy of silence” [Rubinstein, 2013, p. 182], especially on issues relating to taboos.

Notwithstanding the audience’s prior beliefs about topics, van der Bles et al. [2020] found that open communication of uncertainty did not undermine audiences’ trust in facts or communicators. They therefore encouraged “...academics and science communicators to be more transparent about the limits of human knowledge” [van der Bles et al., 2020, p. 7672]. If uncertainty is not successfully conveyed, “decision makers may put too much or too little faith in [the uncertainty]” [Fischhoff and Davis, 2014, p. 13664]. There is an apparent tightrope when dealing with uncertainty and risks, but one that must be walked on, as knowing “specifically how to communicate scientific uncertainty... is essential if patients are to truly share in decision making...” [Simpkin and Schwartzstein, 2016, p. 1714]. Perhaps science communication has something to contribute in the medical space in this regard, and could learn something itself in the process?

Conclusion

In summary, *prima facie* evidence based on existing literature shows that there is a strong potential for science communication practices to collaborate with the medical field to meet the communication needs of hysterectomy patients. Given the many shared challenges described in this commentary, there seems to be a compelling role for science communication and medicine to jointly develop the tools needed to navigate through difficult doctor-patient conversations. Doing so could also help overcome the invisible taboo barriers that have thus far plagued doctor-patient communication, especially in women’s health.

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Authors

Aarti Kapoor is a Ph.D. candidate at the Centre for the Public Awareness of Science at The Australian National University. Her research is in the field of science communication and focuses on the communication of hysterectomy information to Australian women. E-mail: aarti.kapoor@anu.edu.au.

Merryn McKinnon is a lecturer at the Centre for the Public Awareness of Science at The Australian National University in Canberra. Her research interests include the relationship between science, the public and the media; the influence of beliefs on science communication and science education; factors affecting the interpretation and understanding of communication messages; and health communication. E-mail: merryn.mckinnon@anu.edu.au.

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