# Challenges of implementing collaborative models of decision making with trans-identified patients

Jodie M. Dewey PhD

Associate Professor of Sociology, Concordia University Chicago, River Forest, IL, USA

# Correspondence

Jodie M. Dewey, PhD Department of Sociology Concordia University Chicago 7400 Augusta Blvd. River Forest IL 60305 USA E-mail: Jodie.dewey@cuchicago.edu

# Accepted for publication

16 August 2013

Keywords: decision making, qualitative interviews, transgender

#### Abstract

Background Factors health providers face during the doctorpatient encounter both impede and assist the development of collaborative models of treatment.

**Objective** I investigated decision making among medical and therapeutic professionals who work with trans-identified patients to understand factors that might impede or facilitate the adoption of the collaborative decision-making model in their clinical work.

**Design** Following a grounded theory approach, I collected and analysed data from semi-structured interviews with 10 U.S. physicians and 10 U.S. mental health professionals.

**Results** Doctors and therapists often desire collaboration with their patients but experience dilemmas in treating the trans-identified patients. Dilemmas include lack of formal education, little to no institutional support and inconsistent understanding and application of the main documents used by professionals treating transpatients.

Conclusions Providers face considerable risk in providing unconventional treatments due to the lack of institutional and academic support relating to the treatment for trans-people, and the varied interpretation and application of the diagnostic and treatment documents used in treating trans-people. To address this risk, the relationship with the patient becomes crucial. However, trust, a component required for collaboration, is thwarted when the patients feel obliged to present in ways aligned with these documents in order to receive desired treatments. When trust cannot be established, medical and mental health providers can and do delay or deny treatments, resulting in the imbalance of power between patient and provider. The documents created to assist in treatment actually thwart professional desire to work collaboratively with patients.

#### Introduction

Recent scholars have investigated elements that contribute to the process of decision making, such as patient preferences regarding treatment process, and how they present concerns in the medical encounter.<sup>1–4</sup> Both in medical and in mental health work, the development of more collaborative relationships with patients is increasingly important.<sup>5</sup> Some noteworthy investigators are focusing on provisions they believe are required to achieve a co-operative relationship with a patient, such as the establishment of trust and balance of power.<sup>6,7</sup>

# Models of treatment decision making

After the work of Szasz and Hollender<sup>8</sup> as well as that of Emanuel and Emanuel,9 academics have identified models of medical decision making at two extremes; paternalistic models are on one end with more collaborative, informed ones on the other. 10-12 Paternalistic models assume that the professional has all the information and knows what is best for patients<sup>4,5,13</sup>, the clinician's choices are always 'scientifically acceptable', 14 and patients defer to these assessments. 15,23 As a polar opposite, collaborative models of shared decision making and informed consent reflect a shared professional and patient decision-making process, shared ownership, information, treatment options and responsibility for outcomes, as well as re-evaluation of conditions until they agree on the resolution. 4-6,16-19

One key aspect of collaboration is the balance of power between patient and provider. However, these models often do not account for situations where power becomes unbalanced, such as when patients do not agree with the physicians' advice, or about treatment choice for the particular condition, thus rendering discussion about the treatment plan immaterial.<sup>18</sup> Existing research focuses on power as it relates to patient non-compliance or disease characteristics, but does not investigate factors such as institutional support and formal knowledge relating to treatment decisions. It is within these uncharted areas that we begin to grapple with the meanings physicians and therapists give to the process of treating patients and accomplishing their work.

The manner in which collaborative models unfold is based on the unique matters and beliefs patients hold about their lives<sup>2</sup> and the sorts of outcomes they think should occur within the medical encounter. Some choose to defer to professional treatment advice, 5,17,20-24 while others favour more control in the process.<sup>4</sup> Patients' level of involvement may depend on how they interpret their roles and responsibilities as well as the kinds of decisions they expect from their physician. 1,25 The way in which patients present their concerns impacts physicians' and therapists' response. The current literature takes for granted that when conventional patients approach them with common, scientifically legitimate concerns, professionals view their patients as competent and capable of making decisions. Moreover, most medical decisions are protocol-driven, technical and extremely rigid, making discussing treatment options with patients, irrelevant<sup>4,18</sup> or less desired by the physician. 13 On the other hand, McMullen<sup>3</sup> found that diagnosing and treating mental illnesses is not as simple because the aetiology of recognizing and diagnosing, as well as understanding which factors to attribute to the disorder, is complex and variable, often forcing clinicians to work around formal diagnoses.<sup>26</sup>

To date, little to no research exists which sociologically explores how treatment decisions are made from the perspective of medical and mental health professionals; even less research focuses on decisions which affect trans-people specifically.<sup>27</sup> As a group, trans-people represent a diversity of gendered expressions, behaviours, presentations and self-identifications. Those who seek hormonal and surgical assistance and for whom the professionals in this study are treating are individuals who identify and attempt to live in a gender category different from the sex category that they were assigned at birth.<sup>28</sup> How medical and mental health workers make decisions presents a unique case in which to examine whether providers favour and achieve collaboration with this population. Exactly, how to approach trans-people seeking hormonal and surgical interventions is contested ground because some in the medical and therapeutic community view the medical management of trans-people as inappropriate, unethical<sup>29</sup> or that it should be heavily regulated. Even among those most willing to assist, many are ill-prepared or disagree about how to effectively meet patient needs. <sup>27,30</sup> There is a paucity of formal knowledge or education; much of what providers know about treating trans-people comes from their experience with trans-people and from several documents: the Standards of Care, the Diagnostic Statistical Manual and the International Classification of Diseases.

The Diagnostic Statistical Manual (DSM), a document created in the early part of the 20th century by the American Psychiatric Association (APA), is meant to provide diagnostic uniformity for professionals.<sup>31</sup> Initially, the APA introduced the DSM as an alternative diagnostic tool to the International Classification of Diseases (ICD-6), widely used by the rest of the world, claiming it lacked empirical evidence.<sup>32</sup> The International Classification of Diseases endorsed by the World Health Organization is a list of general epidemiological diseases and their management. Despite its initial rejection of the ICD, the APA chose to collaborate with the World Health Organization's writing of the next version of the ICD-8 by creating a section on mental disorders. This strategic move legitimized psychiatry within medicine and increased the international influence of American psychiatry.<sup>31</sup>

Developed in 1979 by the Harry Benjamin International Gender Dysphoria Association (HBIGDA), the Standards of Care (SOC) are clinical guidelines outlining minimal standards for assessing patients' suitability for hormonal and sex reassignment. HBIGDA also created the SOC to protect those who provided such treatments.<sup>33</sup> Building on the ideas of Harry Benjamin, a German-born, American endocrinologist and sexologist, original HBIGDA members believed that surgeries, rather than psychoanalysis, were a preferred method of treatment for transsexuals.31,34 Despite changing the organizations name to the World Professional Association of Transgender Health (WPATH) in 2006, it continues to reflect a mostly American committee.<sup>31</sup> While previous versions of the SOC were based on professional consensus derived from idiosyncratic experiences with trans-people, professional WPATH members claim that the current SOC is substantiated by empirical research.<sup>33</sup> What has not changed between various version is the SOC's adoption of terminology and diagnostic criteria from the DSM and ICD.<sup>31</sup> For example, SOC-6 iterated that gender identity disorders (GID) are mental disorders, drawing support from the DSM-IV and the ICD-10.<sup>28</sup> Increasingly, providers believe that GID in the DSM pathologizes<sup>27</sup> patients, reflects cultural standards of gender rather than objective science<sup>35</sup> and fails to acknowledge trans-people who do not experience mental suffering due to their gender. 36,37

Although historically the SOC drew from the DSM and ICD, today it has legitimacy and impacts future revisions to the ICD and DSM.<sup>28</sup> Launched in 2011, the most recent update to SOC-7 reflects more culturally sensitive language and attempts to better integrate consumers; the burden shifted from the patients' need to prove themselves, to the practitioners' responsibility to assist patients. Finally, the new SOC also clarifies that while being trans is not a disorder, the dysphoria that some experience can be a disorder. Despite these changes, the core requirements making professionals responsible for judging patient competency and proving patients' appropriateness for hormones and surgery have remained largely unaltered. At the time of the interview, my respondents were working under SOC-6 and DSM-IV-TR diagnoses, especially GID. Due to the changes in the SOC-7, the recently released DSM-5 changed Gender Identity Disorder to Gender Dysphoria, leading to discussions about the removal of gender identity from the list of mental health disorders in the upcoming ICD-11.

Therefore, this project is about medical and therapeutic U.S. practicing professionals who assist people who desire to align their bodies with their felt gender by seeking hormone therapy and/or surgery and who therefore must be officially diagnosed with gender identity disorder. I will specifically focus on the balance of

power and trust within the medical and therapeutic contexts, both of which are necessary for collaboration to occur. My work has implications for trans-care specifically and health care more generally.

#### Method

#### Sample

This article stems from a larger study in which I interviewed a total of 43 people, 23 transidentified individuals regarding experiences of discrimination and harassment and 20 U.S. practicing medical and mental health professionals who treat such individuals. I took data from only the portion of the sample who are health providers. I drew my professional sample from the World Professional Association of Transgender Health (WPATH) member list. To obtain my sample, I contacted the then president of WPATH who suggested that I become a member to access contact information for all WPATH members and that I send an email through the member listsery requesting study participation. I sent emails to 60 WPATH members eliciting their assistance. From this list, only 20 professionals agreed to participate.

I decided to include both medical and mental health workers in my sample as trans-people must navigate both to access transitioning services. SOC guidelines compel surgeons and mental health workers to interact, particularly due to the letter requirement. Therefore, I believe it is crucial to interview across disciplines so that I can uncover how each makes sense of treating patients in the light of their interactions with colleagues. My sample includes a sex/gender therapist, an infectious disease specialist, an urologist, an emergency room physician, two licensed clinical social workers, two psychiatrists, two primary care physicians, five clinical psychologists and five plastic surgeons. Although psychiatrists are technically medical doctors, I refer to them as therapists or mental health professionals as their role is similar to that of other mental

health professionals when treating trans-people. I have changed all participants' names and indicate only if they are doctors or medical providers (D) or mental health, or therapeutic (T) providers. I acquired institutional review board as required.

Each interview consisted of nine open-ended questions regarding professionals' knowledge of trans-people, decisions in treating transpatients, and perspectives on difficult and rewarding patients. I asked study participants to describe a recent patient encounter that they would define as rewarding or difficult and to describe in detail how they came to this conclusion. It was important that respondents shared specific details about their treatment decisions in recent interactions with patients and colleagues. When able, I conducted in-person interviews (n = 10); however, I conducted phone interviews for those who did not work in the United States Midwest.

# **Analysis**

I applied grounded theory both in data collection and analysis. Grounded theory is an emergent method; a process by which I involved myself with the data, where simultaneously, I conducted interviews, transcribed previous ones and continually applied inductive reasoning to the codes and themes that emerged from the data.<sup>38</sup> Grounded theory moves inductively, creating theory from the actual experiences of those being studied. To generate theoretical assumptions, I combed through the data looking for emerging and repetitive themes, beginning with broad open coding and then performing narrow, focused coding.<sup>39</sup> Using these themes, I inductively built theoretical perspectives to organize and explain the data. While explicating codes, I continually scrutinized the data to ensure each point earned its placement among various themes. Hence, I essentially performed deductive reasoning, not in the traditional sense of testing large-scale theory but rather to confirm that the theory which emerged from the data was in fact bolstered by the data.<sup>38</sup>

### Study limitations

Very few professionals exist who treat transpeople with enough regularity to gain useful data. Using WPATH was the best way of securing a large enough sample; however, my sample, similar to the entire professional community, is quite small, and because they are all WPATH members, hold similar views regarding trans-care. Although WPATH is an international organization, I decided to focus my study on those medical and mental health professionals who practise only in the United States. I believe that to appropriately compare how providers differ on their treatment decisions, it would be important to investigate professionals who operate under similar systems.

#### Results

Providers' perspective on treatment role

When asked how they see their role in the treatment for trans-identified patients, professional responses varied:

D1: Our goal is not to be gatekeepers but we do take the responsibility of irreversibly altering somebody and from our own ethical perspective we want to make sure that we are doing the appropriate thing so it is not done to make people jump through unnecessary hoops. It is there to make sure as best as we can do to do the right thing for that individual.

While many indicated they did not feel comfortable whether a patient was appropriate for treatment, they did express a sense of responsibility in the decisions patients made. From their point of view, providers felt the need to help patients make a good decision:

D6: My job is to provide enough education that people can make good choices based on sound understanding of the variable. I give them the benefit of a thorough education so they feel that they are making a good choice.

For some, patient competency depends on the absence of mental health issues:

T1: The other big change in terms of the gatekeeper notion...I needed to make a decision about whether this was the right course of action...Over the years I've come to a very different view, which is essentially that if someone comes into my office and as long as they are mentally competent to make decisions about their life...It is their choice as to what they do.

Few providers believed their role was to definitively decide if a patient had gender identity disorder; however, many responses like the one above did show that professionals felt a level of responsibility in ensuring that patients were capable, whether equipped with enough education or mentally healthy enough, to make their own decisions. The tension that emerges as professionals attempt to balance the belief in patient autonomy with professional liability contributes to various treatment dilemmas.

#### Treatment dilemmas

Medical and mental health professionals face dilemmas including the lack of pre-service knowledge in their training and education as a doctor/therapist, as well as reduced institutional support with treating trans-patients.

#### Lack of pre-service knowledge

Almost all respondents indicated that there was little to no formal acquisition of treatment knowledge pertaining to trans-identified patients:

T9: No, it [obtaining information specific to trans-needs] is still additional. To me early on it seemed like a real gap in the knowledge and training of a general therapist... nobody [there] is interested or knowledgeable enough to do it.

T5: If anything it wouldn't be just trans, it would be under a GLBT umbrella. Even in GLBT the T is usually dropped off ...

The absence of education specific to the medical and therapeutic treatments for trans-people translates to lack of institutional support.

D10: You can't make an academic career treating trans [people] so, the academic institutions are not really interested in doing that [offering trans-related programs]..It's not supported social policy.

Professionals, and the institutions that employ them, are ill-prepared and lack support for meeting the needs of trans-people when there is a lack of pre-service academic knowledge. Providers have the challenges of providing good care, educating themselves on how to treat trans-people and being perceived as ethical.

# Lack of supported policy

The unsupported concerns and needs of transpeople cause considerable risk to professionals who treat them. Most expressed concern about the possibility of losing their licence:

T8: The medical people...their licenses were on the line to some extent...And particularly when trans was not in the mission statement, it meant that should a doctor prescribe hormones to somebody and that person for whatever reason sues the doctor, the board would not be likely to support that doctor.

Providers who treat trans-people always run the risk of being perceived as unethical:

D3: Every time I do this (provide hormones to trans-people) you know my license takes a little walk onto a precipice because it is not in the mainstream. If I just put you on hormones do you think any medical board looking at this... they would call me a nut!

To address the lack of educational and institutional support, providers rely on their patients and draw support from treatment documents.

#### Treatment documents

According to the SOC, a mental health professional must diagnose a patient as having GID according to guidelines in the DSM or ICD prior to undergoing hormonal or surgical interventions. The DSM and the SOC help and hamper professionals' ability to treat patients.

DSM. Providers in the United States use the DSM to diagnose, albeit working around it, to effectively treat patients. Although the SOC require a GID diagnosis, many like this therapist agree that 'The DSM diagnoses are still pretty far behind (T1)' while others acknowledge that diagnosing is elusive since 'It's a selfdiagnosis' (D3). Health workers experienced tension in diagnosis, for while the DSM ensures coverage, legitimacy and access to care, it also creates new dilemmas in accomplishing medical and therapeutic work. Debates continue to exist within this small professional community about GID's existence in the DSM:

T1: Is this a disorder or not? And the dilemma is there are advantages to having it labeled as a disorder mainly to get treatment covered and there are disadvantages to not having it called a disorder because people don't like to be told they are

Physicians and therapists grapple with having to diagnose their patients as doing so allows them legitimacy yet can also stigmatize patients:

T3: Well I have to (use DSM diagnoses) in terms of people want to use their insurance... Now I will not give anybody a diagnosis of Gender Identity Disorder. Most of the time it is not covered by insurance, so most of the time they either are depressed or anxious. So that way they can use their insurance, I get paid, and they get their treatment.

To avoid stigmatization and to ensure that insurance will cover their medical/therapeutic services, providers will not diagnose a patient with GID but with an alternative DSM diag-

Although some providers work around a GID diagnosis, many comments such as this one reveal the tension providers experience:

D1: And you learn this isn't a decision that someone made an hour ago that they were trapped in the wrong body you know, and even to this day we follow international guidelines because not in the sense of being a gatekeeper so to speak, but we want to make sure that we are appropriately identifying individuals in my mind that would benefit from surgery. It's still a matter of making an accurate diagnosis and formulating an appropriate treatment plan.

Part of identifying appropriate candidates is also ensuring the absence of other diagnoses:

T4: And then when I say to them 'okay if I could wave a magic wand and turn you into a woman full-time. Would you do that?' Crossdressers would say, 'absolutely not. I am totally fine being a male. I just like [to] dress up and get off being a woman once in a while.' A transgender person would say, 'I'll do anything to be my true gender.' So there is a huge difference there, and there usually isn't a sexual link (for those with GID). If there is, it usually goes away once they are able to start transitioning.

The DSM currently distinguishes between GID and Transvestic Fetishism, where in the former, there is the absence of sexual gratification in the diagnostic criteria. Another requirement for a GID diagnosis is the experience of being in the wrong body from an early point in life. This specification compels professionals to ensure a patient does not have another DSM diagnoses that appears to be GID:

D1: We asked the individual to see the psychologist who was quite convinced that the person had body dysmorphic disorder as opposed to gender identity disorder...sort of a recent shift not the life-long sense of being trapped in the

Fear in losing one's licence constrains many health providers to use the DSM.

D10: I'm not worried about a true trans suing me because they really do better when they have the orchiectomies [removal of the testes for natal males transitioning to female, reduces testosterone]. That's a sign that they were a true trans. That's why I sit on the psychological evaluation. I want to make sure this is a true trans and not somebody who is confused or has some psychosis or something else going on.

As indicated, many providers use the DSM to best treat their patient and protect themselves. When patients do not present in ways aligned with GID criteria, professionals question if perhaps another diagnosis is more suitable. Even when initial patient presentation did conflict with GID criteria, professional respondents felt their diagnostic decision was warranted after providing the associated treatment. In other words, changes witnessed after providing hormones and surgery became the proof that justified the diagnosis. How rigidly or fluidly one administers transitioning treatment expected with a GID diagnosis is outlined in the Standards of Care.

SOC. The SOC are intended to be a tool to assist professionals in the medical and hormonal management of trans-patients. The SOC state that it is meant to be used fluidly; however, one could also deduce a more structured expectation in the process by which patients should transition. For example, the SOC-6 supports that patients must first be diagnosed as having gender identity disorder by a mental health professional who is trained with the DSM-IV and/or ICD-10 criteria prior to receiving hormones or surgery. The SOC-6 also requires and that one must live, at some point, in the chosen gender before accessing gender confirmation surgery and that for some, the real-life-experience may be required prior to receiving hormones. For some, there is a fine line in how to use the SOC. Some providers perceived those who strictly followed the SOC without consideration on how to fluidly apply it to their patients as not providing good

D7: I think a lot of providers use standards of care as kind of their little crutch, or their handicap thing. Like they fall back on it...instead of it being used as a tool to provide good care, they use it (SOC guidelines) as a foundation and if that crumbles, you know, nothing else is really their fault.

Some health workers also felt that those who fail to apply SOC guidelines were not providing good care:

D5: A person who had previously been to someone that did not follow SOC and was butchered...This surgeon did it with no questions

Despite the varying views on how to implement the SOC in patient treatment, professionals often worked around SOC guidelines to meet patient needs:

T4: So often time I will just go ahead, I will write a letter for them so they can go ahead and start hormones...I don't think I should be the one to get in their face and say you have to start living full-time right now today for the next three months before we start giving you hormones.

Although I found many examples of how health workers work around the SOC, often providers would rely on the SOC when they were not comfortable in meeting patient requests:

D3: In other words they thought I was just handing out hormones. Doctor feel-good. I went [to patient] 'I know you are transgendered but there are a lot of steps that you have to go through before we can say you need hormones'.

Regardless of idiosyncratic applications of the SOC, most relied at least minimally on them to reduce liability, as one therapist commented, 'It is not mandatory to use the SOC, but it protects me in a court of law'. The DSM and SOC provide ways of treating and reduce some of the risk in treating. However, they also create new dilemmas when providers must work around them to effectively treat, or when inconsistent comprehension and applicability create tension. These issues further the need for doctors and therapists to establish good relationships with their patients.

#### Reliance on patients

Medical and mental health professionals often found that they had to rely on their patients for effective treatment. In the light of the dilemmas already introduced, health workers stressed the importance of building quality relationships with their patients:

D6: Nobody cares about the relationship between the doctor and the patient when everything goes perfectly. The time that the relationship between the doctor and the patient is so critical is when things don't go perfectly. And that happens.

Establishing a trusting relationship is crucial in providing treatments:

D3: That is going to happen pretty fast for you...[we will] talk about what your life has been and then I can feel comfortable and you can feel comfortable doing this. And then we can trust each other.

One dilemma in having to rely on patients to treat, is the possibility that they may feel compelled to present their concerns within the framework and expectations outlined in the DSM and/or SOC:

T1: Yes and well I can't blame them. They are creating a story of themselves that they believe fits with the identity. They read the literature and they knew back then if they said that they were aroused or used to cross dress as a kid in adolescence then they might not get surgery.

Even though the documents improved, they still present a narrow understanding of gender and dichotomous interpretation of trans-identity (e.g. either one is surgery-worthy or not, one is mentally ill or not). For example, the SOC indicates that while the 'presence of psychiatric co-morbidities does not necessarily preclude hormonal and surgical treatment...(it) may delay or preclude the use of either treatment'.28

T3: And so fairly soon we will have to start working on her (patient) surgery letter and she said 'Sometimes I'm really paranoid that people are reading me... it really pisses me off...' and then she just kind of stopped and said, 'Well you know it is not that bad'. [She was assuming that I thought] That she was walking around way to paranoid and had not gotten to a place inside where she was mentally healthy enough to go through SRS.

Health workers' ability to treat patients and their attempt to accomplish good medical/therapeutic work is compromised when patients feel compelled to present in potentially inauthentic ways:

T9: It seems like in some ways it is a sham. In other words the person sitting with me is there to basically convince me that this is a good idea and there are no problems and I only know what people tell me and so it is not particularly meaningful...

Without initial trust, providers remind patients that to access the services they want,

they will have to adhere to a process with which the professional feels most at ease, as this physician makes clear after telling a patient the process he will need to adhere to as outlined in the SOC: 'I'm it. Tag, I'm it'. (D3) When they cannot achieve trust, providers always have the ability to deny treatment: 'I've turned people down because I don't like them. I think that you have more expectations than I can deliver' (D6).

#### Discussion

This study shares and builds upon some of the same challenges faced by medical and therapeutic providers that have been discussed in existing literature pertaining to decision making. This article advances our knowledge about elements of treatment that impede and assist on collaboration during the medical/therapeutic encounter. As indicated in the literature, trust and shared power between provider and patient allow for true collaboration. However, as the data show, the lack of formal knowledge, institutional support, and an inconsistent understanding and application of the DSM and SOC creates considerable professional risk for those who provide services, especially if professionals perceive a sense of reprisal or that their licence may be revoked. The abovementioned factors related to risk make a trusting relationship between patient and provider crucial, yet difficult to achieve. High risk and the lack of trust tilts power into the hands of the professional as denying or delaying treatment is always a viable option. This fact compels patients to present their gender concerns in ways aligned with existing documents to get the treatments they need, thereby adding to the difficulty in establishing a trusting relationship. Moreover, the aforementioned risk compounded with health insurance requirement for DSM diagnoses, compels professionals to work within existing documents, and hence, further encourages patients to present in a manner consistent with current DSM and SOC definitions and guidelines. Therefore, essentially, each must learn to 'work the system', which diminishes trust between professional and patient and reduces clinicians to mere gatekeepers.

This creates a perpetual cycle of legitimizing outdated knowledge that limits professional ability to assist patients. The documents and the process meant to assist both the professional and the patient actually make establishing trust difficult by tilting power to the providers, thereby impeding on the development of positive professional-patient relationship, making true collaboration difficult to achieve.

The first step to realize true collaboration, balance power, and create the atmosphere for trust to develop, we must first address the inconsistencies evident in the diagnosis and treatment for trans-people. When documents are unclear and institutional support is lacking, insurance companies rather than treating professionals set the rules for how patients and professionals will interact. Future investigation must include how the recent release of the SOC-7 and DSM-5, and the upcoming revisions to the ICD will impact the medical-therapeutic relationship. SOC-7 language claims that treatment decisions are 'first and foremost the patients'. 40 However, before administering hormones, providers must ensure that patients have the 'capacity to make a fully informed decision' and have a well-documented history of gender dysphoria.<sup>40</sup> Recent shifts meant to depathologize, increase patient competency and reduce gatekeeping functions may prove superficial and not impact the actual practices of providers, especially because the requirements placed upon them to diagnose and provide treatments as well as the liability in treating such patients have remained mostly unchanged. These minimum requirements may reproduce the above-mentioned dynamics that limit the establishment of trust by keeping professionals in a gatekeeping role with the task of evaluating patient competency. Additionally, requiring proof as to the existence of dysphoria prior to accessing treatments further forces patients to present a particular narrative which may not reflect their identity or relationship they have

with gender; in other words, the requirement of being 'dysphoric' would mean that patients would have to feel uncomfortable with their gender prior to accessing hormones and surgery, which is certainly not what all experience. Researchers should focus on whether the change in language is enough to impact the subjective views of clinicians or if the core treatment requirements of the SOC, especially the need for a diagnosis based on ICD or DSM criteria, will thwart practitioners' ability to establish trust and build a collaborative relationship with their patients. Finally, as framing these issues as medical vs. mental health concerns greatly impacts definition of problems and treatment for patients, more research should focus on health workers outside the United States who rely on ICD criteria.

# **Acknowledgements**

I am grateful to Dr. Dennis Watson, Dr. Micheal Kenney, Kathy Hegeman, anonymous reviewers, and the editors for helpful comments on previous drafts. The author declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article. The author(s) received no financial support for the research, authorship, and/or publication of this article.

#### References

- 1 Edwards A, Elwyn G. Inside the black box of shared decision making: distinguishing between the process of involvement and who makes the decision. Health Expectations, 2006; 9: 307-320.
- 2 Bodenheimer T, Lorig K, Holman H, Grumback K. Patient self-management of chronic disease in primary care. Journal of the American Medical Association, 2002; 288: 2469-2475.
- 3 McMullen L. Discourses of influence and autonomy in physicians' accounts of treatment decision making for depression. Qualitative Health Research, 2012; **22**: 238-249.
- 4 Montori V, Gafni A, Charles C. A shared treatment decision making approach between patients with chronic conditions and their clinicians: the case of diabetes. Health Expectations, 2006; 9: 25-36.

- 5 Coulter A. Paternalism or partnership? British Medical Journal, 1999; 319: 719-720.
- 6 Charles C, Gafni A, Whelan T. Shared decision making in the medical encounter: what does it mean? (Or it takes at least two to tango). Social Science & Medicine, 1997; 44: 681-692.
- 7 Moumjid N, Gafni A, Bremond A, Carrere MO. Shared decision making in the medical encounter: are we all talking about the same thing? Medical Decision Making, 2007; 27: 539-546.
- 8 Szasz T, Hollender M. A contribution to the philosophy of medicine: the basic models of the doctor-patient relationship. Archives of Internal Medicine, 1956; 97: 585-592.
- 9 Emanuel E, Emanuel L. Four models of the physician-patient relationship. Journal of the American Medical Association, 1992; 267: 2221-2226
- 10 Karnieli-Miller O, Eisikovits Z. Physician as partner or salesman? Shared decision-making in real-time encounters. Social Science & Medicine, 2009; **69**: 1–8.
- 11 Towle A, Godolphin W. Framework for teaching and learning informed share decision making. British Medical Journal, 1999; 319: 766-771.
- 12 Towle A, Godolphin W, Grams G, Lamarre A. Putting informed and shared decision making into practice. Health Expectations, 2006; 9: 321-332.
- 13 Cohen H, Britton N. Who decides about prostate cancer treatment? A qualitative study Family Practice, 2003; 6: 724-728.
- 14 Freidson E. Professional Dominance. New Brunswick, Atherton Press, 1970.
- 15 Cassileth B. Information and participation preferences among cancer patients. Annuals of Internal Medicine, 1980; 92: 832-836.
- 16 Makoul G, Clayman M. An integrative model of shared decision making in medical encounters. Patient Education and Counseling, 2006; 60: 301-312.
- 17 Sackett D, Richardson W, Rosemberg W, Straus SE, Haynes R. Evidence-Based Medicine: How to Practice and Teach EBM. New York, NY: Churchill Livingstone, 2000.
- 18 Whitney S, Holmes-Rovner M, Brody H et al. Beyond shared decision making: an expanded typology of medical decisions. Medical Decision Making, 2008; 28: 699-670.
- 19 Dewey J. Knowledge legitimacy: how trans-patient behavior supports and challenges current medical knowledge. Qualitative Health Research, 2008; 18: 1345-1355.
- 20 Bilodeau B. Degner L. Information needs, sources of information, and decisional roles in women with breast cancer. Oncology Nursing Forum, 1996; 23: 691-696.

- 21 Blanchard C, Labreque M, Ruckdeschel J. Information and decision making preferences of hospitalized adult cancer patients. Social Science & Medicine, 1988; 27: 1139-1145.
- 22 Davidson B, Degner L, Morgan T. Information and decision-making preferences of men with prostate cancer. Oncology Nursing Forum, 1995; 22: 1401-
- 23 Degner L, Sloan J. Decision making during serious illness: what role do patients really want to play? Journal of Clinical Epidemiology, 1992; 45: 941-950.
- 24 McKinstry B. Do patients wish to be involved in decision making in the consultation? A cross sectional survey with video vignettes British Medical Journal, 2000; 321: 867-871.
- 25 Davey H, Lim J, Butow P, Barratt A, Redman S. Women's preferences for and views on decision making for diagnostic tests. Social Science & Medicine, 2004; 58: 1699-1707.
- 26 Whooley O. Diagnostic ambivalence: psychiatric workarounds and the diagnostic and statistical manual of mental disorders. Sociology of Health & Illness, 2010; 3: 452-469.
- 27 Coolhart D, Provancher N, Hager A, Wang M. Recommending transsexual clients for gender transition: a therapeutic tool for assessing readiness. Journal of GLBT Family Studies, 2008; 4: 301-324.
- 28 Winter S. Cultural considerations for the World Professional Association for Transgender Health's Standards of Care: background and recommendations. International Journal of Transgenderism, 2009; 11: 19-41.
- 29 Fitzgibbons R, Sutton P, O'Leary D. The psychopathology of sex reassignment surgery: assessing its medical, psychological, and ethical appropriateness. The National Catholics Bioethical Quarterly, 2009; Spring: 97–125.
- 30 de Vries A, Cohen-Kettenis P, van de Waal H. Clinical management of gender dysphoria adolescents. International Journal of Transgenderism, 2006; 9: 83-94.

- 31 Matte N, Devor A, Vladicka T. Nomenclature in the world professional association for transgender health's Standards of Care: background and recommendations. International Journal of Transgenderism, 2009; 11: 42-52.
- 32 First M, Tasman A (eds). DSM-IV-TR Mental Disorders: Diagnosis, Etiology, and Treatment. Chichester, UK: John Wiley & Sons, 2004.
- 33 Coleman E. Toward version 7 of the World Professional Association for Transgender Health's Standards of. Care, 2009; 11: 1-8.
- 34 Ekins R. Science, politics, and clinical intervention: Harry Benjamin, transsexualism and the problem of heteronormativity. Sexualities, 2005: 8: 306-328.
- 35 Vance S, Cohen-Kettenis P, Drescher J, Meyer-Bahlburg H, Pfafflin F, Zucker K. Opinions about the DSM gender identity disorder diagnosis: results from an international survey administered to organizations concerned with the welfare of transgender people. International Journal of *Transgenderism*, 2010; **12**: 1–14.
- 36 Lev A. Disordering gender identity: gender identity disorder in the DSM-IV-TR. Journal of Psychology and Human Sexuality, 2005; 17: 35-69.
- 37 Bockting W. Are gender identity disorders mental disorders? Recommendations for revisions of the World Professional Association for transgender health's Standards of Care. International Journal of Transgenderism, 2009; 11: 53-62.
- 38 Charmaz K. Grounded theory as emergent methods. In: Hesse-Biber S, Leavy P (eds) Handbook of Emergent Methods, Chapter 7, 1st edn. New York, NY: Guilford Press, 2008: 155-172.
- 39 Emerson R, Fretz R, Shaw L. Writing Ethnographic Fieldnotes. Chicago, IL: University of Chicago
- 40 Coleman E, Bockting W, Botzer M, et al. Standards of Care for the health of transsexual, transgender, and gender-nonconforming people, version 7. International Journal of Transgenderism, 2011; 13: 165-232.