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Physicians' Perceptions of Barriers to Equal Access to Reproductive Health Promotion for Women with Mobility Impairment

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Abstract

In Canada, 15% of women report having a disability, most frequently mobility-related. Research with women with disabilities has for decades brought attention to barriers to reproductive health promotion. Research with physicians regarding why these barriers exist and how they can be dissolved has not occurred. Physicians were recruited through email and pamphlets to participate in 30-45 minute in-person interviews, audiotaped and transcribed verbatim. Charmaz-based qualitative analysis was supported by NVivo10™ software. Twenty-five interviews were conducted before theoretical sufficiency. Six themes were co-constructed: I-Physicians' Perceptions of Barriers; II-Physicians' Perceptions of Consequences of Barriers; III-Resolving Barriers; IV-Physicians' Sub-Understanding of Legal Right to Accommodation; V-Obligation of Physicians to Advocate for Accommodation; and VI-Language Suggesting Physicians' Lack of Understanding of How Persons with Disabilities See Themselves and Want to be Seen. Physicians identified physical access barriers previously identified in critical disability studies literature, but did not identify the barriers of physician attitudes and lack of information provision as reported in this literature. Physicians perceived their additional time for pap smears and other surveillance strategies as barriers, particularly when not remunerated. Physicians were unaware of their legal obligation to accommodate under human rights codes, perceiving that taking extra time to provide accommodation was doing so out of the "goodness of your heart". Physicians used language illustrating many were unaware of how disabled persons see themselves and want to be seen. Education regarding disability rights and culture must be introduced immediately and prominently into all levels of medical education, with the educators being people with disabilities.

Keywords

Physicians' perceptions; mobility impairment; women's health; disability rights; medical education

Background

In Canada, 15% of women report having a disability, most frequently mobility related ("Disability in Canada: Initial findings from the Canadian Survey on Disability," 2013).

Disability impacts health beyond the aspects of health linked to any particular condition (Chevarley, Thierry, Gill, Ryerson, & Nosek, 2006; Kroll, Jones, Kehn, & Neri, 2006; Nosek et al., 2004). The critical disability studies literature has for decades identified barriers to health promotion, prominently citing the way physicians view women with disabilities through the medical model of disability in which they were trained and practice (Linton, 1998; Oliver, 1990; Shakespeare, 2006). This literature insists physicians require training in a social model of disability to understand that social and physical environments that do not accommodate disabled persons create barriers to health promotion (Davis, 2002; Frazee, Gilmour, & Mykitiuk, 2006; Leach Scully, 2008, 2009; Linton, 1998; Mykitiuk & Nisker, 2010; Shakespeare, 2005, 2006; Taylor & Mykitiuk, 2001; Thomas, 2007; Wasserman, Bickenbach, & Wachbroit, 2005).

Multiple studies in the critical disability studies literature have identified many barriers to equal access for women with disabilities to breast and reproductive health (Becker, Staufbergen, & Tinkle, 1997; Beckmann, Gittler, Barzansky, & Beckmann, 1989; Gibson & Mykitiuk, 2012; Kroll et al., 2006; Nosek et al., 1995; Odette et al., 2003). Physical barriers include lack of access to physicians' offices, and lack of appropriate clinical equipment such as height-adjustable (Gibson & Mykitiuk, 2012; Iezzoni, McCarthy, Davis, Harris-David, & O'Day, 2001; Iezzoni, McCarthy, Davis, & Siebens, 2000; Kroll et al., 2006; Yankaskas et al., 2010). This leads to women with disabilities being less likely to receive Papanicolau smears (Smeltzer, Sharts-Hopko, Ott, Zimmerman, & Duffin, 2007; Yankaskas et al., 2010), and other standard obstetric and gynecologic surveillance strategies (Mele, Archer, & Pusch, 2005; Smeltzer et al., 2007).

Women with disabilities are also less likely to be referred for mammograms (Iezzoni et al., 2001; Mele et al., 2005; Smeltzer et al., 2007; Yankaskas et al., 2010), and thus have breast cancer diagnosed at a later stage with higher mortality (Roetzheim & Chirikos, 2002).

The critical disability studies literature has also identified physicians' attitudinal barriers, including the presumption among many physicians that disabled women are asexual (Basson, 1998; Becker et al., 1997; Gibson & Mykitiuk, 2012; Kroll et al., 2006; Nosek et al., 1995; Whelner, 1997), those who are single are celibate (Basson, 1998; Kallianes & Rubinfeld, 1997; Shakespeare, 2000), and disabled women cannot be mothers (Basson, 1998; Kallianes & Rubinfeld, 1997; Nosek et al., 1995), even though it is extremely rare for a disability to hinder a woman's reproductive development or diminish her feelings of sexuality (Basson, 1998; Gibson & Mykitiuk, 2012). These perceptions of physicians may explain their tendency to not provide information regarding contraception and sexually transmitted diseases to disabled women (Becker et al., 1997; Beckmann et al., 1989; Gibson & Mykitiuk, 2012; Nosek et al., 1995). The critical disability studies literature also draws attention to the barrier that physicians perceive that disabled women are heterosexual (Basson, 1998; Kallianes & Rubinfeld, 1997).

As women with disabilities and critical disability studies scholarship has for decades identified barriers to equal access to reproductive health promotion, we sought for the first time to interview physicians to investigate their perceptions as to why these barriers still exist, how these barriers can be dissolved, and what physicians are doing to ensure accommodation for women with mobility impairment to receive equal access to reproductive health promotion.

Methods

Physicians were recruited through email and pamphlets to participate in a 30-45 minute in-person interview. The email and pamphlets included a letter of information and a generic email address to arrange the interview time. Pamphlets were distributed at the offices and clinics of family physicians and obstetricians and gynecologists, and at their grand rounds.

Interviews were conducted, audiotaped (MJ), and transcribed verbatim (MJ, SS) into an electronic format including pauses and voice quality. Open-ended prompts were used to encourage further comment. The qualitative analysis utilized a Charmaz-based approach (Charmaz, 2006) and iterative process. The analysis was supported by NVivo10™ software. During the analysis, data was broken into small, salient codes, using a line-by-line coding strategy (Strauss & Corbin, 1998). Initial coding was followed by a phase of focus coding where the data was re-coded using the salient or significant codes from the previous coding phase. The data was continuously compared for similarities in content. The initial concepts were categorized into preliminary sub-themes and themes. Interviews were conducted with 10 family physicians and 15 obstetrician-gynecologists before theoretical sufficiency was reached.

Methodology

The interviews were unstructured to encourage the physicians to express their personal views directly without discussion with the interviewer. The open-ended prompts were generally reserved to stimulate the physicians to continue their comments and reflect on why the barriers the physicians identified exist and how they can be resolved.

A Charmaz-based approach to qualitative analysis insists acknowledgement that themes do not emerge directly from the transcripts, rather are co-constructed (Charmaz, 2006) with the researchers who bring their lived experience, training, and previous research, to the analysis

process. The researchers performing the analysis and writing (MJ, JN) both had a social model of disability perspective, heavily influenced by their lived experiences and the critical disability studies literature, particularly the work of Catherine Frazee (e.g., (Frazee et al., 2006; Frazee, Gilmour, Mykitiuk, & Bach, 2002)), Tom Shakespeare (e.g., (Shakespeare, 2000, 2006)), Adrienne Asch (e.g., (Asch & Wasserman, 2010; Parens & Asch, 2000)), and Jackie Leach-Scully (e.g., (Leach Scully, 2008, 2009)). The senior investigator’s previous research exploring the effect on disabled persons of emerging and rapidly expanding forms of prenatal “screening” (e.g., (Mykitiuk & Nisker, 2010; Nisker, 2001, 2010, 2012, 2013, 2015b)) likely influenced the development of Themes IV, V, and VI during the writing phase of the research (Richardson, 2000).

This research was only possible because the physicians who participated afforded the researchers “closely-guarded” physician time for the in-depth interviews, and were comfortable sharing their perspectives with the recruiter/interviewer. This was likely only possible because the recruiter/interviewer had recently been accepted into medical school, and the senior researcher had a background in medicine. Although this ‘in-the-club-only’ access is highly problematic for many reasons, perhaps most important because critical disability studies researchers have generally been denied access to physicians for this type of research, physicians may not have participated and so openly shared their thought without it.

Research ethics approval was obtained through the Western University Health Science Research Ethics Board (REB #18985E) and Clinical Research Impact Committee.

Results

Six themes were co-constructed: I-Physicians’ Perceptions of Barriers; II-Physicians’ Perceptions of Consequences of Barriers; III-Resolving Barriers; IV-Physicians’ Sub-

Understanding of Legal Rights of Women with Mobility Impairment to Accommodation that Affords Equal Access; V-Obligation of Physicians to Advocate for Accommodation to Equal Access; VI-Language Suggesting Lack of Understanding of How Persons with Disabilities See Themselves and Want To Be Seen. The Themes and Subthemes are described in Table 1.

Theme I: Physicians' Perceptions of Barriers

Under Theme I are organized excerpts of physicians' comments on the barriers they believe hinder them from providing the same reproductive health promotion and care to women with a mobility impairment as they do with other women in their practices.

I-A: Physicians' understandings of "mobility impairment"

Most physicians understood "mobility impairment" as physical limitations, and many physicians commented on how certain medical conditions make it difficult to properly position patients on examination tables to perform adequate physical exams as illustrated by the following excerpt:

So I've had patients that um are so spastic that their legs can't be open to have a pelvic exam...We were in the operating room and I thought I will have to an abdominal [rather than vaginal] hysterectomy cause her legs couldn't be opened. That's how bad her contractures were.-P11

I-B: Insufficient consideration for accessibility design

All physicians shared the sentiment that clinics and hospitals were insufficiently designed for accessibility, both in terms of structural design and equipment. Insufficient space in waiting and examination rooms was concerning for most physicians interviewed. They commented on rooms being too small to accommodate wheelchairs, and that patients must feel like a "spectacle" or "hassle" when they manoeuvre through the rooms. For example:

...if it's busy...then the person in the wheelchair gets right in the middle of the waiting room in the wheelchair because there's no spot to put a wheelchair...Um, so then, they feel like they're a spectacle in the middle of the waiting room.-P13

and

... [getting] a patient into the clinic room is a, um, is a bit of a bit of a scramble. These rooms aren't very big um, and not well set up to accommodate a wheelchair.- P10

P10, who practices in a clinic in a large hospital, commented that not all doors have automatic buttons to open them:

Go to [our] floor and you'll notice that none of the doors accessing the clinical care areas have automatic buttons opening them.- P10

Similarly P15 reflected on the lack of automatic buttons for her own office which was specifically designed with accessibility in mind, situated above a large modern pharmacy and food store.

Helping patients with mobility impairments move from chairs onto examination tables was frequently commented upon as a significant barrier. A lift can aid with transfer; however, as P4 shares, it can be difficult to access one:

I actually happened to see an older lady...she was wheelchair bound and we had no way to lift her off on to the examination table...I went to the clinical manager...To get that lift, we had to wait 40-45 minutes.-P4

Even in a new large hospital clinic, physicians commented that the number of tables designed to lower to the floor are limited to one.

I-C: Avoid or inadequately perform pelvic examinations

Physicians frequently commented that the gynecologic physical exam is often not attempted or improperly performed on women with mobility limitations:

... it's just impossible or, um, you know, it certainly makes it more difficult to. I mean there are patients who, uh, we've- otherwise I would have done an exam but I've not done an exam just because it's too complicated.-P2

P1 takes some of her patients with mobility impairment to the operating room to perform the exam under anesthesia:

...sometimes we have to book these patients in an operating room, even to examine them, t- to do the examination under anesthesia and, and uh, be able to visualize the uterus and the vagina and the cervix and do whatever we have to do. And sometimes we find nothing, which means that it was a total unnecessary general anesthetic to, to do that.-P1

P13 commented that woman with mobility limitations do not receive care of the same standard:

...we usually try to find a way around it. Um, and and I'm aware that sometimes we may not provide the same equitable care.-P13

P10 states that these challenges often result in cutting corners:

I think the the difficulty in uh physical exams makes the doctors cut corners. And I have to say that is something that I potentially do as well ... I cut corners.-P10

I-D: Additional time requirements

Physicians identified that patients with mobility impairment require more time for physicians to see them:

The time is just amazing. I won't even say it's double the time, it's way more than that...-

P7

and

I may have to do the moving, or help them...But yeah, it always takes more time...Time is always a problem.-P12

and

...I think they should feel fortunate that there are people out there willing to spend more time ... They should consider themselves lucky, I think. And fortunate.-P1

I-E: Insufficient remuneration

Physicians commented that the lack of additional remuneration for additional time spent with patients with mobility impairment may discourage many physicians from adequately caring for those more "difficult" patients. For example:

...a patient that takes you five times longer is not the patient you're encouraged to look after better. Um, that's got everything with to do the way the system has remunerated you.-P10

and

So if somebody's sitting there with this mobility challenge, then yeah, they can take up to an hour of talking to. You get remunerated a little bit for that, but not so much ...-P9

P7 and P9 commented that physicians who do spend time with no financial incentive do so out of their sense of "duty", "conscience" or "goodness of your heart":

...you're spending so much time but then there's no compensation. ...there's nothing to encourage or to pay you for the efforts you have done, except your own conscience that you've done something good. You've done your duty.-P7

and

...over-extending or extending oneself as care provider or team care provider is to try and, essentially the goodness of your heart, provide for these patients.-P9

However, one of the family physicians commented:

...maybe in fact uh, if you don't have that many patients who are, have uh disabilities, um, you've had a bunch of fast physicals that you got paid for...and you sort of probably made a ton off of them in some ways because you didn't have to spend the same length of time as an average person... And now you have to spend a little bit more time.-P12

I-F: Need for additional support personnel

Physicians identified that patients with mobility limitations often require support personnel such as nurses, clinic assistants, family members, support workers, and hospital volunteers. Physicians commented that making arrangements to ensure that there is enough help is a challenge:

...I would be nowhere if my, um, patient in a wheelchair didn't come with her husband who can lift her I don't have a good setup to do this with a patient on her own.-P10

and

Human resources, ah, far exceed the human resources required for a patient who's fully capable. For the person who's fully capable, you can argue they don't need any human resources. They just grab their car keys, get in the car and come. Person who's disabled may require everything...-P9

P7 referred to nursing cutbacks making it even more difficult to find help for patients requiring additional support:

From nursing point, I mean there's so many cutbacks. We don't have that many nurses like we use to have before. As it is you're working with very basic skeletal staff.-P7

I-G: Physicians' assumptions in discussing sexuality with women with mobility impairment

The assumption of physicians that women who are mobility impaired are not interested in discussing sexuality and topics of reproductive health were commented on by physicians as factors influencing the quality of reproductive care the women receive. For example:

.... I imagine having a mobility issue or really anything externally that makes you seem different, um, would pose a barrier to being open about issues of sexuality or questions about sexuality.-P3

and

...the struggle that these women have with their self-image [swallows], some of them almost feel asexual because [clears throat] they can't respond like they're supposed in the sexual area. And, they feel very inadequate, umm.-P6

and

I imagine that the physicians make a lot of assumptions, right? So meeting a patient for the first time for example, who's wheelchair bound, um, many physicians may assume that she's not sexually active and that contraception shouldn't even need to be discussed for that reason.-P3

I-H: Physicians' attitudes of defensiveness

P3 commented that it may be the collective attitude of defensiveness among physicians that is preventing them from recognizing that their own attitudes are influencing patient care:

...There's a lot of, sort of defensiveness, I think. Um. We take pride in the fact that we're a self-regulated profession and believe that you know, we're everything we do is the best we can do is the best we can. So it's sometimes more difficult to digest, um, that maybe

we're not doing that, that we could be doing better for a population of patients that we as a, as a community of physicians may be marginalizing without even realizing it.-P3

Theme II: Physicians' Perceptions of the Consequences of Barriers

Physicians spoke of the consequence of the barriers faced by women with mobility impairment in accessing care.

II-A: Delayed Diagnosis

Many of the physicians interviewed commented that women with mobility limitations are not receiving standard health promotion strategies, particularly screening and surveillance. Pap tests and mammograms were repeatedly mentioned as screening programs in which women with mobility limitations often do not participate. For example:

I have had patients who have never had a pap smear.-P10

and

Some of these women haven't had a pap in twenty, thirty years...because their family doctors can't get them on the [table]...-P11

and

I think there's a, ah, at a primary care level possibly, um, probably, a barrier to seeking preventive health um care, preventative health care at a primary care physicians office.

Even something as simple as having a Pap smear or pelvic examination and just you

know, who's around in the clinic to help...-P9

and

I think all mobility impaired people will have... the majority of malignancy diagnosis late because of delaying the investigations...They don't come as frequently for examination,

they cannot have a good examination, they cannot have investigations at the spur of the moment.-P7

II-B: Marginalization

A few participants felt as though some of the barriers women with mobility limitations faced in clinics and hospital marginalize them:

...we don't always remember to do things a certain way. And and then we'll find out the wrong way. For example, they'd get there for the test and it can't be done. Um, and uh, and then you just feel badly that you've put them through that uh feeling of being different from other patients.-P13

and

...our examining gowns...I'm just thinking back to the patients that are obese. I know they feel like we don't have gowns that fit them properly, you know, and um that's not really, I mean that makes you feel marginalized and makes you feel like there's something wrong with you because the, the one size doesn't fit.-P3

II-C: Physicians' perception of patients' attitudes to barriers

This subtheme was co-constructed from comments physicians made in regards to the attitudes patients with mobility limitations had in coping with barriers encountered in accessing reproductive health promotion and care:

Patients have many frustrations. If they end up being seen and um, getting care, they don't really complain too much. I've not had too many patients complain about it.-P10

P2 and P9 commented that patients with mobility limitations may not complain because the mobility impairment is often a lifelong issue to which they have become accustomed:

Most of these patients they know that, it's a, it's a lifelong issue for them so for them it's no worse than anything else. I mean, they don't complain too much, uh frankly.-P2

and

...I've noticed very little frustration with the limited mobility because they're used to that.

They live that, day in and day out.-P9

Some physicians have witnessed anger, frustration and negativity, and felt as though patients with mobility limitations were not appreciative of their healthcare practitioners:

There is a negative uh attitude sometimes. So they get...they get snappy at you for every small things, even though you're trying so hard to help them. -P7

P6 felt that patients appreciate the care the clinical team provides them and imagined what the patient might be thinking:

I would say it's pretty common for them to say, 'well, most people were very kind and supportive. And although they may not show very much about what I [the patient] was going through, they tried to be as helpful as possible. They made sure when I was up on a table [clears throat] that there was somebody there watching to make sure that I didn't fall off, because I really have no control over my legs. And if my legs fell off the edge of the table I'd just tumble off so that they made sure somebody was there watching.-P6

Theme III: Resolving Barriers to Equal Access Health Promotion and Care

Physicians offered strategies as to how the barriers they identified in providing equitable care could be resolved.

III-A: Greater involvement of allied health professionals

Greater involvement of allied health professionals was felt important by physicians as one way of ensuring patients with mobility impairment have optimal health promotion and care:

For myself w-w-we'll sort of involve a nurse case manager, social worker, have them contact people and umm make arrangements for people to come to us.-P9

and

...bring it up with colleagues who are more knowledgeable. The physical therapy people in the profession [swallows], so they might add anything to your support or it may be worth a consultation for them to see the individual. But broaden the base and intensity of support as best, as much as you can.-P6

To ensure women with mobility impairment receive adequate screening and surveillance, P10 and P12 encouraged physicians to refer these women to clinics and physicians where exams and procedures can be performed with greater ease and familiarity:

I think they should refer. Refer to someone who's more um, familiar with it. And I think that doesn't always happen...But there are many family doctors that are amazing in doing pap smears, so I don't really want to...discourage family doctors from trying harder.-

P10

III-B: Allocate more time

Some physicians commented that simply spending more time with patients with mobility impairment would result in better care. P9 and P6 comment on the importance of using the extra time to explain the various options to patients with impairment including possible modification from the standard of care:

I think you have to be willing to spend sufficient time to be able to explain what the standard of care is and what the deviation is that's gonna be imposed by their limitation in mobility and the perceived detriment is to their health cause of that deficit in standard of care.-P9

III-C: Improvements in accessibility design

Insufficient clinic and equipment accessibility design was a barrier cited by many physicians (Theme IB); however, physicians were skeptical about improvements being made in the near future:

The hospital level, I'm sure there's lots that can be done from an infrastructure and physical environment standpoint. Umm...I guess a little bit jaded and skeptical about what, what I could, what I would actually see them doing... one would imagine that adjustable examining tables and umm spacious waiting rooms and things like that – those sort of accommodations – would be uh present....I don't see them knocking down any walls to make the [laughs] examining rooms bigger or the waiting rooms bigger, or anything like that.-P3

P5 commented that efforts should be made to have at least the "bare minimum":

I don't necessarily think every room need to be, you know, adapted, but, um, to at least have, space that can be used, I think is important to make sure that there's, y'know, that piece is there. Um, and and I guess that sounds like doing the bare minimum, but I think bare minimum is better than nothing.-P5

Some participants commented that having government funding and regulations to make clinics accessible may increase the likelihood seeing accessible design:

... I think it would be wonderful to have funding for us to maybe have um, some adjustment to our beds or a lift in the office...if the government had grants for medical facilities, we could have that, you know, it would be a one-time investment... -P13

and

...particularly I think in healthcare, there's, you know, there is and there should be regulations around ensuring these patients are able to gain access.-P5

III-D: Additional government compensation for physicians

To justify additional time and effort required to care for patients with mobility impairment, additional financial compensation was the most popular solution physicians suggested:

... There ought to be a premium that says, "Look, if your patient's limited mobility is defined by criteria A, B, C, D, or E, then you're gonna get paid fifty-percent more just for having her as your patient ... as opposed to you, you just say, "hi you're too complicated" and refer her to somebody else...-P9

and

You know, it makes sense. Right? Right now we have um, um, with the new um, capitation funding um for age. We have a premium on physicals for anybody over 70 because it takes longer. Um and I just saw a memo about medically complex patients that they're also adding something in. And it makes sense because um, it-it-it does take longer and yeah.-P13

and

I think that if the remuneration were there, you know, it's amazing, it changes your mindset from you know, "why can't I just get onto my next patient", which is the aggravating issue now.-P9

and

The simple solution would be for the government to have premiums, like a limited mobility premium that you could tack on from a, you know, like a, a very basic approach uh to the problem, I guess. Um, and that potentially may accommodate for that extra time that needs to be spent. What that looks like, I don't know... from a solution standpoint, that's probably would be the quickest, the quickest and probably the most effective way...-P5

While commenting on the need for additional remuneration, P7 states that it will not be the single answer for resolving barriers to care:

...there should be some remuneration but I don't think that's the answer for everything. That's not going to solve everything...maybe they will not be ignored as much. But um, it won't change the whole problem...-P7

P14 commented that evidence for incentives for changing physician behaviours is not as convincing:

I think our reasons for acting the way we do are more complicated than that. P14

Despite the popularity of increased remuneration, several physicians recognized that it would be difficult to define "mobility impairment", and that without proper criteria, the premium could be abused:

The problem then becomes who is really impaired...-P12

and

...there are people, unfortunately in our profession that can also abuse. So as soon you put mobility impaired, anything everything can count. Yeah. So it's difficult to define the criteria.-P7

III-E: Education

A few physicians commented on the lack of education and experience in caring for women with mobility impairment during their medical training:

...Like I've, we've, I cannot recall ever having grand rounds or any specific targeted education towards talking about this patient with, with mobility extra needs from a mobility standpoint. Um, and so maybe that's why it hasn't really been on my, my radar that much.-P3

and

... I probably should have seen some, some younger patients but, I think it's just kind of the way and the context in which we do most of our learning and, maybe those patients just don't happen to end up you know, in the delivery rooms and maybe they, they aren't pregnant, I'm not sure...-P5

and

[In medical training] I'm not sure I had a patient that has had such limited mobility um that you know for example she's been in a wheelchair or has no use of her limb like lower limbs for example.-P3

and

I think that...physicians would be reasonably adaptable to ah CME, or a grand rounds on limited mobility...I think we respond by in large pretty well to you know, umm, here's a

body of literature around this patient population. We're gonna think about this patient population for a while here and we're gonna think about health issues related to this patient population.-P9

and

I think we also need more training. ...In our CME's we don't really talk about this. I mean, we have, we always, I guess um, a lot of CME is drug company driven sometimes. Even even the ones that are university-credited. Um, so um, topics like this don't get addressed all the time ... the one thing gets plugged in our CME all the time is cardiovascular risk because it ties into statin prescriptions and all that. So it would be, the more hear things, the more um it's on our radars.-P13

III-F: Specialized clinics

Finally, some participants believed that establishing specialized clinics for women with mobility limitations may ensure that they have access to the services required to maintain their gynecologic health:

I-I mean ultimately the, you know, another solution may be to establish an actual clinic um specifically for-, I-I guess the problem with this idea is that, obviously then I'd kind of boxes them into a separate category.-P5

and

...it may be that the it uh, they're better served in facilities where there's nurse practitioners with different models of cares.-P11

**Theme IV: Physicians' Sub-Understanding of the Legal Rights of Women with Mobility
Impairment to Accommodation that Affords Equal Access to Reproductive Health**

Promotion and Care

Theme IV was co-constructed during the writing phase of the research at which time it became evident that the physicians who generously donated their time to be research participants in this study were unaware of their legal duty to provide women with mobility impairment the same high quality of reproductive care as they provide their other patients so as their care would be non-discriminatory under human rights codes. For example,

...I think they should feel fortunate that there are people out there willing to spend more time and ah, there is, ah, they have the proper facilities to accommodate them. They should consider themselves lucky, I think. And fortunate.-P1

and

They think that, it's their right to, to have all this ah, you know care given, ah in the clinic. And an- and if you tell them that "well, no, we have to take you to the operating room to do this", sometimes they get angry, angry at our, frustrated, thinking that we don't want to do, or we don't want to help them.-P1

In the following excerpt, P13 misunderstands the legal obligation of physicians to provide accessible care as being "kind", and goes on to say that his actions were "unusual":

I had somebody who had had a stroke and uses a walker. And um, we had to arrange a psychiatrist for her and the psychiatrist realize that he was in a non-accessible building. So she would have had to walk up a flight of stairs and uh – and actually that particular psychiatrist was really kind and he arranged to come here and see her, which is extremely unusual but he was very kind.- P13

Theme V: Advocacy

V-A: Physician advocacy

P5 emphasizes the difference that physicians can make if they advocate for their patients.

I think physicians really are a group that can make a lot of change with respect to this.

Um, so that's why, I mean that's one of the things I'd love to see more of...as physicians take on a bit more of these advocacy positions...we may be able to...really lead support and make that, the case louder.-P5

P3 comments on how physicians would like to advocate for individual patients, but systemic barriers make them less likely for physicians to voice their concerns:

I think on an individual level most people want to be advocates um, but I think that sometimes that again, those system barriers lead to skepticism and uh and make you less, less likely to put yourself out there, put as much effort forth to address those barriers.-P3

V-B: Patients as advocates

Some physicians comment that patients with mobility impairment should advocate for themselves to increase awareness of challenges they face:

...why can't we encourage the people who have disabilities to come forward and spread the word in the community? ... So I think the, the message can come more strongly from them, or from their families, I don't know. -P4

P13 supports patient advocacy by commenting on patients who were strong advocates:

I have a couple of patients who are really vocal and-and that's wonderful because they're their own advocates and advocates for other people.-P13

P11 was less optimistic about how well women with mobility impairment could effectively "mobilize themselves" to participate in self-advocacy:

We have to wait for them to speak for themselves. And sometimes that's a long time...Will it ever happen? ...they have to mobilize themselves. It has to be a bottom-up.-P11

Theme VI: Language Suggesting a Lack of Understanding of How Persons with Disabilities See Themselves and Want To Be Seen

Theme VI was also co-constructed during the process of writing, following the other stages of the qualitative analysis, when it became apparent that many of the comments of the physicians were noted to contain language suggesting a lack of understanding of how persons with disabilities see themselves and want to be seen. For example, P4 described a patient as "wheelchair bound". P4 saw a mobility impaired woman as "special" and "brave" which could be considered paternalistic:

She was very thankful by the end of it. She said you did not make me feel uh any less of a human being. I said, 'of course. You are special, you are brave, I admire you.' -P4

The following comment shares a belief that people with disabilities are chronically ill and "disadvantaged":

The thing about limited mobility is um, it it inspires because it draws at the root of why people are in medicine, which is to help the disadvantaged, or the sick or the unwell. People with limited mobility are all of those things.-P9

The use of the word "regular" in the following excerpt suggests that people with mobility limitations cannot live their lives like "regular" people:

... when a person has been mobility impaired, can't enjoy life in the regular way.-P7

Similarly, P9's use of the word "capable" for patients without mobility impairment, suggests that those with mobility challenges are "incapable":

For the person who's fully capable, you can argue they don't need any human resources. They just grab their car keys, get in the car and come. Person who's disabled may require everything....-P9

Similarly, P10 refers to women having no mobility limitations as being "normal" and "regular" patients therefore implying that those with limitations are not:

I find the patients in wheelchair are a good pregnant patients just like normal pregnant patients...A patient in a wheelchair or a patient unable to mobilize um, um as a regular patient....-P10

P7 feels pity for those with mobility limitations, and describes how we cannot truly empathize with the challenges they face:

Y'know, able-bodied people can't actually, really can't realize how bad it is for them.-P7

P7 also implies that those with mobility limitations are unfortunate, and that their challenges have been unfairly handed to them by God:

...you have to be really calm and understanding in say, 'yeah its okay. Let them say nasty things to you [M laughs] because the God has not served them the right hand' or something like that.-P7

Discussion

This study confirms in physicians' own words what research with women with disabilities in the critical disability studies literature has reported for decades: (i) there are many barriers to equal access for women with disabilities to health promotion (Becker et al., 1997; Beckmann et al., 1989; Gibson & Mykitiuk, 2012; Kroll et al., 2006; Nosek et al., 1995; Odette

et al., 2003); (ii) physicians see persons with disabilities as being broken and having deficits that need to be fixed, and thus lack understanding of how persons with disabilities see themselves and want to be seen (Linton, 1998; Oliver, 1990; Shakespeare, 2006, 2014); (iii) physicians lack of awareness of their legal obligation to provide accommodation for women with disabilities (Frazee et al., 2006; Gibson & Mykitiuk, 2012); and (iv) critical disability studies, including the social model of disability must become prominent in all levels of undergraduate and postgraduate medical education, with the educators being persons with disabilities (Linton, 1998; Carla Rice, 2012; C. Rice et al., 2017; Shakespeare, 2016).

Although the physicians interviewed confirmed many of the physical barriers to access identified in the critical disabilities studies literature, such as lack of height-adjustable exam tables (Becker et al., 1997; Kroll et al., 2006), physicians did not identify their lack of providing important information as a barrier (Basson, 1998; Kallianes & Rubenfeld, 1997; Nosek et al., 1995; Shakespeare, 2000). For example, although physicians commented on being uncomfortable in discussing sexuality with women with mobility impairment, they did not see their discomfort as a barrier, rather believed the barrier to discussing sexuality was the woman with mobility impairment. For example, “...*having a mobility issue or really anything externally that makes you seem different, um, would pose a barrier to being open about issues of sexuality or questions about sexuality*” P3. Further, our research confirmed that physicians perceive women with disabilities to be asexual, to not respond sexually, and to not require information on contraception and prevention of sexually transmitted infection (Basson, 1998; Becker et al., 1997; Beckmann et al., 1989; Gibson & Mykitiuk, 2012; Kroll et al., 2006; Nosek et al., 1995; Whelner, 1997). For example, “...*the struggle that these women have with their self-image, some of them almost feel asexual because they can't respond like they're supposed in the sexual area.*”

And, they feel very inadequate” P6; and “Many physicians may assume that she’s not sexually active and that contraception shouldn’t even need to be discussed for that reason” P3.

Some physicians spoke of barriers not previously identified in critical disabilities studies research, as women with disabilities and critical disability scholars do not perceive these as true barriers. For example, physicians identified as a barrier the extra time and effort it takes them to provide gynecologic surveillance such as pap smears: “...a patient that takes you five times longer is not the patient you’re encouraged to look after better...” P10; and “...you’re spending so much time but then there’s no compensation...”P7. Physicians suggested introducing a mobility-impairment premium into their payment schedules, as a possible strategy to resolve this barrier. However one physician commented: “...maybe in fact uh, if you don’t have that many patients who are, have uh disabilities, um, you’ve had a bunch of fast physicals that you got paid for...and you sort of probably made a ton off of them in some ways because you didn’t have to spend the same length of time as an average person... And now you have to spend a little bit more time” P12.

As the physicians interviewed for this study volunteered their “protected” time for this research, they were likely more interested than the average physician in resolving barriers to health promotion for women with mobility impairment. Thus their comments indicating a lack of understanding of the legal rights of disabled persons were surprising and suggest other physicians would have even less understanding. For example, “... [women with disabilities] should feel fortunate that there are people out there willing to spend more time ... They should consider themselves lucky, I think. And fortunate” P1. Women with disabilities should not have to feel fortunate that a physician will provide accommodation for equal access to health promotion, but rather expect equality and non-discrimination as is their legal right. In Canada,

provincial Codes prohibit discrimination against people based on disability ("Canadian Human Rights Act, RSC 1985, c H-6," 1985; "Human Rights Code, RSO 1990, c H.19," 1990), grounded in Canada's Charter of Rights and Freedoms ("Canadian Charter of Rights and Freedoms," 1982; "Canadian Human Rights Act, RSC 1985, c H-6," 1985; "Convention on the Rights of Persons with Disabilities ", 2006; Frazee et al., 2006; Frazee et al., 2002; "Human Rights Code, RSO 1990, c H.19," 1990). Further, Canada is a signatory of the United Nations Convention of the Rights of Person with Disabilities ("Convention on the Rights of Persons with Disabilities ", 2006) which guarantees non-discrimination in health care for persons with disabilities . Many of the physicians interviewed, rather than being aware of their legal obligations, perceived that any extra time and effort for accommodation for women with mobility impairment was provided out of the "*goodness of your heart*" P9. If physicians were trained in a social model of disability, they would understand that providing accommodation for patients with a disability is their legal duty, so financial or other incentives to accommodate women with disabilities would be inappropriate. Lack of understanding of legal right to equal access to health promotion for women with mobility impairment underlines the need for the critical disability studies to be prominent in all levels of medical education.

It was similarly surprising that some of the well-intentioned physicians who volunteered for a study investigating barriers to equal access for women with disabilities used language that displayed lack of knowledge of how disabled persons see themselves and want to be seen. For example, P4 saw women with mobility impairment as "special" and "brave", and P9 "*The thing about limited mobility is um, it it inspires*". Simi Linton (1998) draws attention to the use of "well-meaning" and "nice words" that "are rarely used by disabled activists and scholars (except a palpable irony), that though may be "well-meaning" convey the "do-gooder mentality endemic

to the paternalistic agencies that control many disabled lives". The physicians interviewed also used terms such as "*wheelchair bound*" P4, with, we believe, no ill intention disrespect or disempowerment, but illustrative of their lack of understanding the social model of disability in which women with mobility impairment prefer the language of "uses a wheelchair". P9 continues with "*people are in medicine...to help the disadvantaged, or the sick or the unwell. People with limited mobility are all of those things*" which demonstrates the medical model of disability lens through which physicians see persons with disabilities (Oliver, 1990; Shakespeare, 2006, 2014). The medical model is further illustrated by P10 referring to women not having mobility impairment as "*normal*" and "*regular*" patients, implying that those with mobility impairment are not "*normal*" and "*regular*". The language of not "*regular*" was also used by P7 "*... when a person has been mobility impaired, can't enjoy life in the regular way*", and P10 "*A patient in a wheelchair or a patient unable to mobilize um, um as a regular patient...*". Similarly, P9's use of the word "*capable*" for patients without mobility impairment, suggests that those with mobility challenges are not "*capable*". Using language suggesting women with mobility impairment are not capable illustrates that physicians do not recognize the lack of their capability of Canada's health and social systems as failing to insist on and operationalize accommodation. Clearly the physicians interviewed were unaware of the vast critical disabilities studies literature that emphasizes the importance of language that puts the "person-first" and uses "words with dignity" (Devlieger, 1999; Fernald, 1995; Lynch & Groombridge, 1994). Physicians' lack of understanding of how persons with disabilities see themselves and want to be seen further emphasizes the need for critical disability studies to be immediately introduced into all levels of medical education.

Although physicians were able to identify physical barriers to the health promotion of women with mobility impairment, they expressed skepticism rather than dedication in regards to the required changes for accessibility to health promotion. For example, "*Umm...I guess [I'm] a little bit jaded and skeptical about what, what I could, what I would actually see [the hospital] doing... one would imagine that adjustable examining tables and umm spacious waiting rooms and things like that – those sort of accommodations – would be uh present....I don't see them knocking down any walls to make the [laughs] examining rooms bigger or the waiting rooms bigger, or anything like that*" P3. Instead of dismissing barriers such as small rooms as "*the nature of the beast*" P1, physicians have the legal obligation under human rights codes ("Canadian Charter of Rights and Freedoms," 1982; "Canadian Human Rights Act, RSC 1985, c H-6," 1985; "Human Rights Code, RSO 1990, c H.19," 1990) and the professional obligation in their Royal College of Physicians and Surgeons of Canada role as patient advocate (Frank, 2005; Frank, Snell, & Sherbino, 2015) to push for changes that would ensure equal access for women with mobility impairment.

Our research clearly confirms the urgent necessity of including critical disabilities studies prominently in all medical school curricula, residency programs, and continuing medical education courses, and that the educators must be persons with disabilities (Linton, 1998; Carla Rice, 2012; C. Rice et al., 2017; Shakespeare, 2014) both in curricular development and presentation of the content. As Simi Linton (1998) points out, health education curricula suffer from "the absence of disabled peoples' perspective in the general culture", and in the education process (pp. 114, 115). Indeed the physicians interviewed in our research recognized their lack of exposure to disabled persons in medical training in comments such as "*...I cannot recall ever having grand rounds or any specific targeted education towards talking about this patient with,*

with mobility extra needs from a mobility standpoint. Um, and so maybe that’s why it hasn’t really been on my, my radar that much” P3; and “[In medical training] I’m not sure I had a patient that has had such limited mobility um that you know for example she’s been in a wheelchair or has no use of her limb like lower limbs for example” P3. One physician blames the lack of disabilities-related education in continuing medical education programmes on the fact that the funding of these programmes is largely by pharmaceutical companies: “...In our CME’s we don’t really talk about this...a lot of CME is drug company driven sometimes. Even even the ones that are university-credited... the one thing gets plugged in our CME all the time is cardiovascular risk because it ties into statin prescriptions and all that” P13.

The comments of physicians in our research illustrating that physicians view patients with disabilities as having problems and being a problem for the cost efficiency of their practice, emphasize the need for a social model of disability to replace a medical model in all levels of medical education. Tom Shakespeare (2014) insists, “rather than pursuing a strategy of cure or rehabilitation, it is better to pursue a strategy of social transformation” (Shakespeare, 2014) (pp. 12). Simi Linton (1998) describes the medical model of disability as casting “human variation as deviance from the norm, as pathological condition, as deficit...” (pp. 11) and calls for curricula to “develop more valid and useful approaches to the presence of impairment in the population and disability in society, and respond to disabled people in a less deterministic and more integrated way” (pp. 114, 115). Michael Oliver (1990) writes that seeing disabled persons as problems “...ignores the influence that cultural or even subcultural factors may have upon the disease process.”

Tom Shakespeare’s (2014) imperative that a social model approach to disability replace the traditional deficit approach, would help physicians understand that disabled persons are not

problems that needed to be fixed, it is society that needs to be changed (Shakespeare, 2014).

Emphasizing the social model of disability in all levels of medical education, would combat the deficit model entrenched by extensive medical education on prenatal testing to prevent disabled persons. Under a medical model, “a child with a genetic mutation is viewed differently from under a social model where the same child is healthy but requiring social accommodation” (Mykitiuk & Nisker, 2010). With the rapid expansion of new prenatal “screening” technologies and their industrial promotion (Asch & Wasserman, 2010; Mykitiuk & Karpin, 2016; Mykitiuk & Nisker, 2010; Nisker, 2015a; Vanstone, King, deVrijer, & Nisker, 2014), the medical model of disability will become even more entrenched in physicians’ perspectives of disabled persons.

Persons with disabilities should create the medical education curricula, and facilitate its content in person, through electronic formats, and arts-based strategies (Linton, 1998; Mykitiuk, Chaplick, & Rice, 2015; Carla Rice, 2012; C. Rice et al., 2017). Recently Project Re-Vision, a large Canadian research and education project led by Professor Carla Rice (Carla Rice, 2012), has created a bank of digital stories, written and performed by women with disabilities (Mykitiuk et al., 2015; C. Rice et al., 2017) that should be essential curriculum material at all levels of medical education.

This study was only possible because physicians allowed the researchers through their carefully-guarded doors, and afforded the recruiter/interviewer (MJ) a significant amount of their closely-guarded time. This access was likely due to the recruiter/interviewer having been just accepted into medical school when the recruiting began. Of course this ‘in-the-club’ only access is highly problematic for many reasons, one of which is denying critical disability studies researchers the in-depth physician interviews that occurred for this study. As in all qualitative research, the findings cannot be generalizable beyond the views of the research participants, the

researchers, and the location of the research. The physicians interviewed practiced in Southwestern Ontario with a population of 2.5 million, in urban and rural regions. Most of the obstetricians interviewed practiced in hospitals affiliated with a university medical school.

Conclusion

The physicians interviewed in this study confirmed physical barriers to equal access to reproductive health promotion for women with mobility impairment previously identified in the critical disability studies literature, but seemed unaware of their attitudinal barriers. Rather, the physicians’ comments confirmed the critical disability studies literature that contends physicians see women with mobility impairment as asexual and celibate, and fail to provide these women the information on contraception and sexually-transmitted infection they would for “regular” patients. Physicians also appear unaware of their legal duty to provide accommodation under human rights codes so as not to discriminate against a woman with mobility impairment. Physicians commented that rather such accommodation is provided out of the “goodness of your heart”, particularly if time-consuming and non-remunerated. Some physicians used language insensitive to how women with disabilities see themselves and want to be seen, illustrating that medical training lacks exposure to persons with disabilities and the critical disabilities studies literature. If physicians were trained in a social model of disability, they would understand that social and physical environments that do not accommodate disabled persons are the etiologies that cause barriers to equal access to health promotion to exist. Education regarding disability rights, disability culture, and the social model of disability must be included prominently in all medical school curricula, residency programmes, and continuing medical education courses. The

educators must be people with disabilities, either in person or through digital storytelling and other arts-based strategies.

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