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Perceptions of Women with Infertility on Stigma and Disability

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Abstract Women with fertility problems have utilized the Americans with Disabilities Act to sue to gain insurance coverage for fertility treatments and additional paid time away from work, thus requesting that the relatively invisible but stigmatizing condition (infertility) be acknowledged by society as a disability. This provides a seemingly paradoxical situation given the generally negative connotation of disability in our society. Twenty-three in-depth interviews were completed with women who belonged to infertility support groups to examine their experiences of infertility, stigma and the notion of constructing infertility as a disability. We took a constructivist grounded theory approach to the data by engaging in free coding of themes. Being a mother was something respondents assumed would happen naturally for them, within the realm of a normative life course. The discussion of infertility as a disabling condition brought forth issues of stigma from respondents in terms of a feeling of non-normalcy and discredited social status surrounding the childless state. A primary issue that arose in discussion with respondents was resource allocation, and the potential for a label such as 'disability' to afford more generous reimbursement and workplace support for infertility treatments. There is an interesting juxtaposition between the individual problem of infertility and the social consequences of a childless state. Legal discourse reveals that simply being labeled disabled does not necessarily increase access to treatment if treatment is sought. Further study is needed to assess the potential social, medical and legal ramifications for all stakeholders of labeling infertility a disability.

Keywords Infertility · Stigma · Disability · Social construction · Gender · United States

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Introduction

The condition of infertility creates difficulties for women who wish to have a biological child. Among these difficulties are the stigma associated with infertility and its costs—physical, psychological, emotional and financial. Although women and men tend to be equally susceptible to infertility with approximately 33 % of the cases experienced to each [1], most treatments are focused on women. One of the ways in which this can be explained is that men's fertility is linked almost solely with the quality of their sperm while women's fertility is linked with a complex of reproductive organs, hormones, and psychosocial environments [2]. Women also make up the majority of workers that claim to be affected by discrimination in the workplace due to infertility [3].

In recent decades women with fertility problems have sued insurance companies and employers to gain insurance coverage for fertility treatments and additional paid time away from work to pursue them. In several legal cases, The Americans with Disabilities Act of 1990 has been used as a basis to demand that infertile women achieve equal access to the financial resources to attain treatment, thus framing the condition of infertility as a disability [for examples, see 4–8].

In lawsuits that attempt to construct infertility as a disability individuals with a relatively invisible but stigmatizing condition (infertility) are requesting to be formally acknowledged by society as disabled. This provides a seemingly paradoxical situation given the generally negative connotation of disability in our society. In this project we explore, through the analysis of 23 in-depth interviews with women experiencing infertility, the felt role expectations and accompanying stigma that arises from infertility, the potential labeling of infertility as a disability, and the social implications of applying such a label to the inability to physically bear children.

Background

According to data collected for the National Survey of Family Growth, approximately 10.9 % of all women in the United States experience impaired fecundity (meaning it is difficult or impossible to get pregnant or carry a pregnancy to term) at some point in their lives [1, 9]. Reproductive technology has advanced rapidly since the first documented artificial inseminations in the early 1900s. Today, fertility treatments range in scope from hormone treatments, chemical induction of ovulation, in vitro fertilization (with parent or donor specimens) to surrogacy. These advancements, while increasing options and possibilities for women to have biological children, have also increased the pressure to do so despite lower levels of success and higher risks than spontaneous pregnancy [1, 10–12].

The average cost of in vitro fertilization in the United States in 2011 was $12,400 per cycle, yet currently only 14 states have insurance legislation that mandates insurance coverage for fertility treatments [13, 14]. Additionally, infertility treatment is generally not covered by Medicaid, a policy which often prohibits low-income women from partaking in infertility services [15]. Treatments occur on a demanding schedule and include frequent doctor's visits, time away from work, and additional downtime at home to recover from treatment side effects [16]. The treatment cycle can also be both physically and psychologically distressing, as each month there is a rigid treatment protocol to follow, dramatic mood swings to manage, ovulation to occur, and, potentially, egg retrieval followed by insemination [11, 16–20].

Research on women's contemporary lives shows that there are many ways women are still held back from achieving personal and professional goals due to constraints placed on them to maintain traditional gender roles, particularly as relates to motherhood [21–24]. ''For women especially, parenthood may be considered a master status in the sense that motherhood casts its shadow over other statuses and permeates the performance of a wide range of social roles'' [11:1008; 23 and 25 also reported]. Not fulfilling motherhood expectations is often grounds for women with infertility to experience a deep sense of distress and incomplete womanhood [11, 26, 27]. Therefore, infertility has been described as a ''major disruption in one's projected life course, a failure to live up to normative notions about what it means to be a woman in American society'' [19:101].

Crawley et al. [28] have constructed a model that helps to explain how gendered messages, such as the importance for women of maintaining the social role of mother in order to fulfill norm expectations, give rise to gendered consequences, for example the continued difficulty women face in achieving workplace equality due, in part, to their reproductive capacity. Through the feedback loop of performativity and surveillance, gender norms, such as the expectation that women must bear children in order to be fully feminine, to be a complete woman, are continually reinforced and reified. In this way, they claim gender becomes equated with sex and is viewed as an innate rather than achieved way of being. Women may feel that achieving motherhood is an innate need or desire rather than a social expectation and, thus, the linkage between women's reproductive bodies and the constraints of inhabiting a woman's reproductive body, are also reinforced and reified. Accordingly, it is considered women's social responsibility to overcome fertility problems in order to have a biological child as a ''…women with no children still represent[s] the ''other'' in societies that value children and motherhood (even if this value is not structurally supported)'' [23:359]. Therefore, the lack of control over becoming pregnant when one wishes to is both a life course issue and an issue of social responsibility.

Thus, women who experience infertility must negotiate their interactions with others based on social expectations regarding marriage and family, medicine and healthcare, work and caretaking, the self and the body. Infertility can negatively affect their marital relationships, particularly when one spouse wishes to continue with medical treatments and the other does not [29, 30]. Obtaining medical treatment can add to feelings of failure and marginalization [31–33]. These perceptions are reinforced through their interactions with sometimes insensitive or unknowing health care personnel and through the invasive nature of the medical procedures they endure [17, 34–36]. Additionally, women who seek fertility treatments must account for repeated time away from work for doctor's visits and recovery from treatment [37]. This can lead to perceptions of poor job performance, ability and commitment by superiors as well as to resentment from coworkers [37]. In implementing policies that address female reproduction as extra, additional or voluntary [38], employers, insurers, litigators and judges are separating the body system of one gender from the other when determining whether or not infertility is a disabling condition.

Infertility as a Stigmatizing Identity

Infertility and infertility management can lead infertile women to experience different types of stigma: felt and enacted [39], self and public [40, 41]. Felt stigma involves perceptions of the stigmatized person that they are being labeled, stereotyped, or isolated from/by others [39]. In response, this person may self-stigmatize, incurring negative beliefs about themselves, loss of self-esteem and self-efficacy, and thus tend to isolate themselves from others, including their own in-group [40]. Enacted stigma refers to actual status loss and specific acts of discrimination towards an individual [39]. In public stigma these status losses and acts of discrimination are towards a stigmatized group [40]. Given the continued emphasis on biological motherhood in United States culture, it is not surprising that many studies indicate women feel marginalized and viewed as deviant or abnormal when they cannot or do not become pregnant and give birth to children [11, 17, 18, 26, 42–46].

Felt and enacted stigma as they relate to the experience of infertility are closely tied to notions of discredited and discreditable identities as well as self and public stigma. A discredited identity is one that is observable; from which one cannot ‘pass’ as normal in day-to-day interactions. A discreditable identity describes the internal perception of a potentially stigmatizing condition or attribute that is not directly observable or publically announced [18, 46–49]. In past research infertility has primarily been treated as a discreditable attribute—one with primarily individual consequences that can be voluntarily hidden from others. Infertility has also been described as a ‘‘secret stigma,’’ one that causes individual women to feel distress, a loss of self-esteem and self-efficacy, tendencies of self-stigma [10, 11, 18, 41, 46, 50].

Indeed, infertility can be hidden from others for varying periods of time; for the most part, as there are no outward signs of disease or distress. However, once infertility issues have been discovered or disclosed the stigma associated with infertility must be managed. Infertility in the case of public disclosure, or through attempts to manage disclosure, becomes a discrediting attribute with distinct social and economic consequences. It is these perceptions of enacted and public stigma through a discredited identity that may influence individual women to selectively disclose their condition to only a few trusted companions (i.e. through contact), engage in behavior that prevents such disclosure (i.e. self-stigma), or strategically manage disclosure to attain greater resources and support (i.e. challenging them through public protest, education and litigation) [40, 41, 51, 52].

Infertility as a Disability

The main body of literature on disability indicates that stigma increases when one ‘‘becomes’’ disabled. Although laws, such as ADA and ADAAA (American with Disabilities Act Amendments Act), provide grounds for geographical mobility, health services, employment opportunities, and access to technology and education, many people with disabilities still find their lives difficult and their freedoms limited [53, 54]. The legal discourse reveals that simply being labeled disabled does not necessarily increase access to treatment if treatment is sought. However, through formal recognition of a diagnosis as disabling, stigmatization of a condition may in fact decrease [54, 55].

In the recent past, women with fertility problems have pursued the diagnosis of disabled through bringing suit against insurance companies and employers to gain healthcare cost coverage of fertility treatments and additional paid time away from work to pursue them. In a number of these cases, infertile women have sought these rights by claiming that reproduction is a major life activity—an essential element in medico-legal terms for acknowledging a condition as disabling [for example, see 4–8]. As seen in the case of Saks v. Franklin Covey [8], gaining acknowledgement as being disabled does not guarantee funding for their treatment or accommodations for their condition. The number of cases brought that have employed the narrative of disability is small, perhaps due to rulings as seen in the Saks case. However, the number of married couples who experience infertility is reportedly increasing and the social stigma of childlessness persist at the same time as technological advances in treatment are being made, healthcare costs continue to rise and new federal health insurance laws are being enacted. This current analysis expands upon the theoretical understandings of infertility as a stigmatized identity by exploring the juxtaposition of women's infertility experience with the politico-legal discourse on infertility as a disability.

Methods

Data and Respondents

Data for analyses came from in-depth interviews conducted over a period of 6 months with 23 women who identified themselves as experiencing infertility. A conscious decision was made to utilize the internet via national advocacy and support groups to make interview contacts. Previous researchers' have had successful experiences using websites to find more diverse samples [56–60]. Hamilton and Bowers [56] suggest that finding the most appropriate hub or hubs is crucial to optimizing diversity and in ''recruiting individuals interested in that specific research question.'' Women who had or were experiencing infertility were the respondents of interest for this study. For this reason, leaders of infertility support groups whose names, site locations, and e-mail addresses were publicly posted under the auspices of a national coalition, were located in 8 Midwestern states and were contacted via e-mail to request access to respondents.

Responses were obtained from five support group leaders in four states, two of whom were located in the same city. Group leaders agreed to announce the request for interview respondents at their meetings, as well as post flyers describing the study at infertility support group meeting locations, support group websites and via e-mail. Most groups had mailing lists that consisted of fewer than fifty people therefore a goal of interviewing ten percent of the group size was set or at least five women from each site. Kvale [61] notes that this is a suitable sample size as it is provides a large enough number of interviews from which to determine if there are any consistent and recurrent patterns in this data and it is small enough that to be able to obtain a deep understanding of the each participant's experience. Individual respondents with interest in participation then contacted the first author, who made appointments and traveled to a location of the respondent's choice for the interview.

Approximately 2 weeks before the interview was scheduled to take place the respondent was sent a letter of confirmation that contained an informed consent document, a confirmation letter and an initial questionnaire to provide preliminary/introductory information prior to the interview, along with a self-addressed stamped envelope. The respondent recruitment processes as well as the questionnaire and interview guide were approved by the Institutional Review Board prior to initiation of the study.

The women were predominately white (87 %), self-identified Christians (78 %) financially secure, and well educated. Average age of respondents was 33 (range 26–40), 70 % were educated beyond a Baccalaureate degree, and 78 % had a total household income over $70,000 annually. All of the respondents were currently married, and each of the respondents had health insurance coverage. Most of the women had been pregnant at least one time, but 75 % were childless at the time of the interview. The in-depth interviews were semi-structured; a series of questions were developed prior to the interview based upon the existing infertility literature. However, the goal of the interview was to create a conversational atmosphere where the respondents could openly discuss their perceptions of infertility, stigma, and disability with the interviewer. As previously noted, interviews took place in a location that chosen by the respondent in order to provide them with a sense of comfort and control before, during, and after the interview. Additionally, information from the pre-interview questionnaire provided information regarding each respondent's individual situation and was used by the interview to help build rapport and guide specific topics of conversation. Interviews were recorded for transcription and varied in length from 1 to 2.5 h.

Analysis

We took a constructivist grounded theory approach to the data by engaging in free coding of themes, events, actions, attitudes and phenomenon, in order to organise them into an understandable, descriptive form. A constructivist grounded theory approach assumed the emergence of multiple realities within a provisional and socially constructed context. Although all of the respondents were experiencing a similar situation, infertility, we interpreted data using the assumption that the phenomenon of infertility could be interpreted in multiple ways from multiple vantage points [62]. Thematic categories emerged through line-by-line coding. Once a set of thematic categories/concepts was clarified, a second level of coding was employed in order to make determinations regarding the ''events, happenings, objects, and actions/interactions that [were] found to be conceptually similar in nature or related in meaning'' [63:102]. The categories that emerged from this second level coding were further reduced through a third level of coding into subcategories by reexamining the details within categories and determining similarities and differences between them. Finally, selective coding was used to refine or integrate categories into central explanatory concepts [63]. Data saturation was reached at the point when no new codes or themes emerged during the interviews or from the data.

Findings

Failed Motherhood

The narrative descriptions of stigma and infertility nearly all began with the respondents' story of their desire to have children. These stories revealed that being a mother was something they assumed would happen naturally for them, within the realm of a normative life course, as reported in previous studies on women with infertility [11, 23]. A typical response to the opening question ''Tell me about the first time you realized that you were having problems getting pregnant or maintaining a pregnancy…'' was that they always wanted to have or be around children, to have a baby, and to be a mother.

Desperation was a theme often linked to this seemingly natural desire to be a mother. This theme was seen throughout the data and here was linked to going into debt in order to try and fulfill that desire:

> I'm so desperate (laugh) to have a baby that (pause) you know
> sometimes I kinda need him saying ok wait a minute [we don't have
> the money right now] and then on the other hand (pause) there have been
> times when we have gone a little bit into debt for a month or two to
> pay for [a treatment].

The themes of desire and desperation were tied to the subtheme of difficulty being around other people's children. Whether it is in day-to-day visits or special events, many women's stories revolved around these types of encounters. In this passage, the feeling that all of their friends have children compounded feelings of desire for their own children:

> You know we'll go to our friend's house and all my friends have
> kids and they'll be playing and we'll leave and say, we've gotta have
> a kid now. I can't handle seeing all these little kids.

And here, a typical social and religious event, baptism, was difficult to attend due to the number of infants involved in the ceremony. In addition to satisfying her need to support her friend, this woman also related her need to protect her husband from her negative emotions concerning attending this event:

> We went to my best friend's baby's baptism, on Sunday morning, and
> There were like eight babies there being baptized. It was my own personal hell.
> And afterward we were supposed to go to her house for a meal, and I couldn't,
> I couldn't do it. I made it through the baptism, I smiled, I congratulated her and
> her family, I kissed the little guy on the top of the head, and I said to myself, I
> can't do this, so I looked up at her and made up some[thing—I] said I've got a
> test, I've got to go and I got to the jeep and was welling up and thought, I'm
> not going to do this, I'm not going to do this…[I: And that was because of your
> husband?] Yes, because I know he is worn out.

Women in this study reported that dealing with other women's pregnancies was particularly frustrating for them. During these periods they reported experiencing status loss [39] and disappointment in finding that those they felt were ''knowing'' supporters [64:688] would also provide unsolicited, unhelpful advice. This was particularly noteworthy where women noted it seemed that everyone else they knew was getting pregnant—and without difficulty. In this passage, the respondent noted that it never occurred to her that getting pregnant would be a challenge for her:

> All my friends you know they start trying and then [in] a few months you know,
> they've got a big belly and they're on their way but it just never never dawned
> on me that (pause) I would have any trouble what so ever.

Here, the woman related her sister's ease in getting pregnant and having children—and her frustration at her own difficulty in doing so:

> And my sister just had her their, well her third child, but she has four children
> total. And bam, bam, bam. My mom had no problems getting pregnant, you
> know. You see women all the time have you know, have no trouble getting
> pregnant. And my body can't do this one thing. And I find that very frustrating.

As the claims regarding their non-normative status unfolded, women began to relate them to the discrediting nature of their status as non-mothers. In particular, many of the narratives included descriptions of friends, family, and even strangers asking when they were going to have children. This phenomenon of asking personal, uninvited, intrusive questions, is referred by Cahill and Eggleston as ''open-person'' treatment [64]. As these women were married and of childbearing age, people appeared to feel that they had a warrant to demand an explanation of their non-normative status. The following story began with questions from a religious leader. It was not unlike other narratives found in this data set that involved relating a series of interrelated events and experiences that were used as grounds for their feelings of stigmatization.

> I've been married a year. Already! Our priest came up to us who is also my husband's cousin, and he's a Monsignor, Monsignor came up to us and said, so when are you [two] gonna have kids? When, oh no, am I gonna have some baptisms pretty soon? Other people have consistently come up to us and and that's hard. That's hard to handle.

The effects of the condition of infertility in conjunction with its stigmatising characteristics can create difficulties in marriages [20, 30]. The following was a typical, albeit brief, account of marital difficulties found in the data:

> The biggest struggle I'm dealing with right now is that the infertility has caused a huge problem in our marriage, yes, to compound everything else…and there are others in the support group who are having marital troubles as well.

Stigma Management: The Dilemma of Disclosure

The data reflected a continuum of strategies to manage stigma through disclosure rather than because of disclosure as suggested by Goffman [47] and Greil [17, 18]. The disclosures women talked about contained specific patterns that we associated with types of concealment and disclosure: selective, therapeutic and preventive [51]. All three types have to do with managing perceptions of both those who disclose and those to whom a disclosure is made. Therapeutic disclosure involved ''telling'' of the condition or treatments a woman was undergoing to become pregnant so to receive more empathetic treatment from those to whom she has disclosed this information. Preventive disclosure, was used when women released information regarding their infertility prior to inquiries from others in order to control perceptions of themselves as women, workers and potential mothers. Here, a report of selective concealment was employed wherein the condition of infertility was considered too private to share with others unless support is sure to be offered. A doctor is reported as advising against telling anyone about the condition.

> I feel like it's just a private thing, and I don't need to share it with just everybody. I share it with those who I feel like will be able to support us. I guess. I don't share it with people that I feel like are not going to be supportive Or [are] not gonna be able to handle it. I know I've heard like my sister in law said her doctor told her not to tell anybody.

Here, therapeutic disclosure was employed; meaning disclosure was made to a certain group of people likely to provide much needed emotional support. Proximity as well as regularity of contact appeared important in the decision to disclose to her condition to this group of friends:

> I've kind of (pause) communicated with [long distance friends] less because it's felt like I never had anything say it other than oh another fertility cycle failed… We play cards with some friends from church every Saturday night, or every Friday night, and then my group of girlfriends that I hang out with are from church and so (pause) you know everybody's talking about what's going on with their kids or their families or you know whatever, and so when everybody's talking about their ups and downs that's when I'll talk about what's going on. A lot of times, they'll ask specifically so (pause) a lot of times it's also after a failed cycle. (pause) I'll bring it up because that's when it's tough so you know they just listen, sometimes they cry with me and give me a hug.

The decision to disclose, and if so to whom mainly revolved around whether or not disclosure would garner support and resources and/or result in fewer questions and less unsolicited advice. For example, in the following passage hurtful comments and strong opinions about infertility treatments are cited as reasons for not disclosing:

> One reason I don't tell some people is there are people who are incredibly umm… the opposite of thoughtful, whatever that is, I can't think of the word I want right now. There, I've had people say some very hurtful things to me. There are people who have very strong opinions about fertility, infertility treatments, and like I said, my friend does. And, there are others, and so I am careful… about who I tell for those reasons.

Sometimes an onslaught of unsolicited questions, comments and advice resulted in women feeling a need to disclose their condition in order to prevent further infringement on their privacy. Preventive disclosure may quiet questions but may also lead to further more intrusive ones. In this example, the man making the comments was given the benefit of the doubt but his willingness to treat his acquaintance as an open person does highlight the notion that women who are childless are not meeting their societal obligations.

> And he, we, well you know, made comments…And I said, you know, it's, it's not that easy for everybody to have kids, and once you've been in my shoes, then you would understand that you kind of have to make sacrifices and decisions, and figure out what the priority is. So, you know, it, it, he probably wasn't thinking. But that kind of cut, you know, cut me. I mean, sure yeah that's great, I'd love to have three kids of my own at home, but that's not the way it's working right now. So… what do you do?

Infertility as a Disabling Condition

The social construction of infertility as a disability has its roots in discrimination cases brought against employers by individual employees. None of the respondents had heard of the discrimination cases or had discussed the proposal that infertility may be a disability with others. Therefore, applying the label of disability to an infertile condition was not an emergent theme from our data, but instead was elicited through a series of directed questions. However, when presented with a question addressing the potential for infertility to be labeled as a disabling condition, all but one of the respondents reacted positively and felt that such a classification would make resources available to infertile women.

The discussion of infertility as a disabling condition brought forth issues of stigma from respondents in terms of a feeling of non-normalcy and discredited social status surrounding the childless state, and concerns regarding the disclosure of status that would arise from a public label. A primary issue that arose in respondent discussions was resource allocation, and the potential for a label such as 'disability' to afford more generous reimbursement and workplace support for infertility treatments. The following quote provides an example of a woman who had not considered a disability label previously, but felt such a label had potential to assist those women who currently have few resources to attain infertility treatment.

> I suppose if people can recognize you know that you have a medical condition and that it is I don't know that (pause) I don't know I haven't thought about that being a disability–is it really a disability versus some of the other programs that we have? I guess I would have thought FMLA would've been more, something

> within that, but I suppose, yes, people will look anywhere they possibly can to find support, you know…and I have to consider that I am in a privileged position. Otherwise, I wouldn't be able to pursue treatment…so really, maybe this makes good sense.

In the following statement the narrative concerned basic life functions. This is an interesting turn because the ADA definition of disability includes the restriction of one or more ''major life activities.'' Even without being familiar with the ADA definition, this respondent intuitively made this leap:

> You know if you are looking at it more from a legalistic or medical definition then you're looking at basic life functions, you know a basic life function is to, is definitely having children.

The majority of the responses concerning the potential of defining infertility as a disability conveyed a similar message to this respondent's statement:

> It is definitely a disability…physically and psychologically. Your body can't do what it is supposed to without help…the treatments themselves are disabling… and, whether or not you are able to use technology to overcome it and become pregnant you never graduate from having infertility…

For the women in this study, the possibility of claiming a disabled identity provided evidence of an authentic medical condition to present to those who questioned, blamed, or advised them otherwise. They also asserted a label of disabled would be useful in procuring access to treatment to overcome their condition and have a biological child. Here, the respondent recounted her efforts to educate her insurance company regarding her treatment. She compares their denying her claims to denying treatment to a cancer sufferer, a disease that this respondent perceives to be considered a legitimate and disabling medical condition by those with the authority to allocate resources.

> I have big rants about that with health insurance companies like that's like telling a cancer patient, we'll diagnose your cancer but not fix it. Their argument, and I've actually had this argument with an insurance company on the phone before because [they won't pay] and their argument is (pause) having children is elective. My response to that is you're right. People choose to have kids. However, if they can't have kids that is not their choice, it is disease just like cancer is disease.

She also noted that infertility was a unique experience, a unique form of disability. A number of women noted that infertility is unique because sufferers must experience the failure of their treatment, and the ensuring disappointment, on a monthly basis. In response to an interviewer question regarding defining infertility as a disability, the respondent noted:

> You know, I know it had been at least a year. So it must have been oh-five. And, um, thinking why isn't, you know, why isn't this working and then you know, it's just kinda like um, an, an ongoing rollercoaster. You know? It's, it's kinda like okay, you, you try and then you get your period. And then you continue to try and then you get your period. And so you've got all this hope, and, and that this is gonna work this time, and then you know, you start getting cramps and then you get your period. And then, just the longer you go on through this process, the

> worse it gets. You know, the worse the kinda the roll, the emotional roller coaster gets.

However, one respondent was adamant that infertility is in no way a disability. She indicated that she thought labeling infertility a disability in order to make treatments more financially accessible would be like ‘‘using a sledgehammer…to drive a nail.’’ She felt that there were probably other means, such as seeking insurance mandates, which would be more appropriate solutions.

> It’s not a disability…you don’t come in a wheelchair or cane or with umm huge glasses on or you know…If that’s the only way to get the coverage that that is being sought than obviously then sure that makes sense but it seems like (pause) you know it [labeling infertility as a disability] seems like you know using a sledgehammer (laughs) you know (laughs) to you know to drive a nail, you know like maybe just a regular little hammer would be ok, you might damage the drywall in the process you know what I mean?

Discussion

In our study we examined the role of stigma in the experiences of women facing infertility, and expanded upon the discussion of stigma management to address the conceptualization of infertility as disabling or a physical disability. There is an interesting juxtaposition between the individual problem of infertility and the social consequences of a childless state. The body was described as separate from the self when considering infertility as a medically treatable condition and integrated with the self when considering how vital the body is to identity—and to becoming a biological mother. Across the narratives, respondents expressed that their bodies were letting them down and were uncooperative, causing them serious emotional pain and casting doubt on their ability to fulfill their role in society. The ability to have biological children was, therefore, of premier importance to them and made overcoming the physical constraints of the body through access to and use of assisted reproductive technologies vital to overcoming the stigma of failed motherhood. It must be noted, however, that respondents were contacted on the basis of membership in an infertility support group, and therefore were likely to have deeply considered these issues prior to interview. Our findings highlight the salience of the motherhood role among a sample of women who are involuntarily childless, and may not reflect the experience of a wider population.

All of the respondents but one considered infertility physically and/or psychologically disabling. Overall, the primary theme that emerged from the discussion surrounding stigma, infertility and disability was that the women felt that having the label of disabled would provide them with the necessary means to arm themselves to challenge both public and enacted stigma in order to better manage their own identities as women [see 55, 65]. Most respondents believed that being able to call themselves disabled would lessen the stigma of infertility itself. There was a perception that the label would provide evidence of their pain and legitimize their condition, thus lessening the perception they were somehow less than whole women. This is paradoxical in a sense, given that the disabled label carries its own stigma in our culture. The use of a disabled label to achieve credibility is a social phenomenon that would benefit from further examination using a more diverse sample and multiple methods, such as an analysis of legal documents or court transcripts from the cited cases. Additionally, disability did not spontaneously emerge from the data, but instead was elicited directly from interviewer questions. While this method was appropriate for our initial, exploratory study of respondent perceptions on this topic, results would be strengthened by further or expanded interviews where perceptions of disability may emerge more spontaneously.

In prescribing an overarching medical definition of infertility under this rubric, women constructed narratives of ‘‘boundary repair work’’ [66:538] wherein further medicalization of their condition might help them regain control over their bodies, via more accessible and affordable treatment, and over their lives, via legitimization of their condition. However, few respondents discussed potential negative ramifications such as discrimination when applying for insurance coverage or employment. The assumption was made that such a label would improve circumstances as opposed to bringing on further stigmatization and discrimination.

The positive response to the suggestion that infertility be labeled a disability mirrors the responses that Thoits [55] notes in her work with women who sought treatment for mental health problems. Women in her study with higher levels of education and income were more likely to reflect about their condition and actively seek ways to mitigate its effects. For the women in this study, the possibility of claiming a disabled identity would provide evidence of an authentic, ongoing medical condition to present to those who questioned, blamed, or advised them otherwise. They also asserted that they would find this label useful in procuring access to treatment to assist them in achieving their goal: giving birth to their own child.

Providing a legal label of ‘‘disabled’’ for women with infertility would not, however, guarantee access to resources. The right to be labeled as disabled is considered a negative right that has been upheld for women with infertility in some number of court cases. Negative rights focus on individual rights: the rights for safety, self-determination, and privacy. The obligation of others from a negative rights perspective is not to interfere with or impede these rights. Positive rights afford individuals access to public resources in order to pursue those activities. In the majority of court cases where women gained rights to the label of disabled due to reproductive deficits, rights were constructed as solely negative—no positive right to resources was generally recommended or enforced [for example, see 5].

However, there is a recent rebirth in the legal and medical discourse on gaining positive rights for those with infertility. In this discourse, the notion that infertility is a disability is upheld by citing the Americans with Disabilities Act, ADA Amendments Act, United States Department of Justice, World Health Organization and United Nations definitions of both conditions [34, 67–69]. In constructing infertility as a disability, claims are made that it will not only help relieve stigma and discrimination, it will also increase access to treatment and health outcomes.

Conclusion

In this study we link women’s experiences of infertility, stigma management techniques and the social construction of infertility as disability. In so doing, we were able to illustrate the parallels between individual women’s perceptions of designating infertility as a disability alongside the legal and medical discourses on disability. A primary limitation of this study was the use of a sampling strategy that accessed respondents through infertility support groups. Because women self-select to seek support for their condition, it is likely that the women in our sample have identified their infertility experience as more salient than women who elect not to seek such support. For example, women of differing culture, age, education, ableness, functional status and marital status may vary in the ways they conceptualize infertility as well as in the types of social support available to them. Additionally, the women in our sample were generally white and highly educated, perhaps reflecting access to support groups or infertility treatment and information, as is the case in clinical samples. While future research in this area would benefit from a larger, more diverse sample across demographic and fertility categories it is of interest that the women we interviewed were financially stable and had access to insurance benefits for at least some infertility treatments. In spite of this fact, the women in this study felt that they did not have access to sufficient levels of care to help them fulfill their goal of becoming a biological mother. The findings in this study suggest that they would find the categorization of infertility as a disability advantageous—both financially and socially. However, the legal discourse reveals that simply being labeled disabled does not routinely increase access to treatment if treatment is sought. In the current healthcare reform debates, reproductive healthcare is contentious and often framed as a ‘‘woman’s issue.’’ Further study is needed to assess the potential social, medical and legal ramifications for all stakeholders (women, spouses, families, employers, healthcare providers and financiers) of labeling infertility a disability.

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