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Ophra Leyser-Whalen
University of Texas at El Paso, oleyserwhalen@utep.edu

Arthur L. Greil
Alfred University, fgreil@alfred.edu

Julia McQuillan
University of Nebraska - Lincoln, jmcquillan2@Unl.edu

Katherine M. Johnson
Tulane University, kjohns25@tulane.edu

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"Just because a doctor says something, doesn't mean that [it] will happen": Self-perception as Having a Fertility Problem among Infertility Patients

Ophra Leyser-Whalen,[1] Arthur L. Greil,[2]
Julia McQuillan,[3] Katherine M. Johnson,[4]
and Karina M. Shreffler[5]

1 Department of Sociology and Anthropology, University of Texas at El Paso, El Paso, Texas, USA
2 Division of Social Sciences, Alfred University, Alfred, New York, USA
3 Department of Sociology, University of Nebraska–Lincoln, Lincoln, Nebraska, USA
4 Department of Sociology, Tulane University, New Orleans, Louisiana, USA
5 Human Development and Family Science, Oklahoma State University, Stillwater, Oklahoma, USA

Corresponding author — Ophra Leyser-Whalen, The University of Texas at El Paso,
Department of Sociology and Anthropology, 500 W. University Ave.
El Paso, Texas 79968, USA; *email* oleyserwhalen@utep.edu

Abstract

Only some individuals who have the medically defined condition 'infertility' adopt a self-definition as having a fertility problem, which has implications for social and behavioral responses, yet there is no clear consensus on why some people and not others adopt a medical label. We use interview data from 28 women and men who sought medical infertility treatment to understand variations in self-identification. Results highlight the importance of identity disruption for understanding the dialectical relationship between medical contact and self-identification, as well as how diagnosis acts both as a category and a process. Simultaneously integrating new medical knowledge from testing and treatment with previous fertility self-perceptions created difficulty for settling on an infertility self-perception. Four response categories emerged for adopting a self-perception of having a fertility problem: (i) the non-adopters – never adopting the self-perception pre- or post-medical contact; (ii) uncertain – not being fully committed to the self-perception pre- or post-medical contact; (iii) assuming the label – not having prior fertility concerns but adopting the self-perception post-medical contact; and (iv) solidifying a tentative identity – not being fully committed to a self-perception pre-medical contact, but fully committed post-medical contact.

(A virtual abstract of this paper can be viewed at:
https://www.youtube.com/channel/UC_979cmCmR9rLrKuD7z0ycA).

Keywords: infertility, diagnosis, treatment, self-definition, identity disruption, symbolic interactionism

Introduction

Medical sociologists contend that health and illness can be understood as socially constructed categories negotiated by professionals, sufferers, and others within socio-cultural contexts. The study of illness experience is an important focus within social constructionism that examines the ways in which sufferers subjectively define their experiences and manage their everyday lives (Conrad and Barker 2010, Pierret 2003). Much research on chronic illness experience centers on biographical disruption (Becker 1994, Bury 1991, Williams 2000), self-perception implications (Bury 1982, Charmaz 1990), and lay illness perceptions (Chrisman 1977, Mabry 1964, Strauss and Glaser 1975). While sufferers' illness conceptions are shaped in interaction with medical professionals, professional and sufferers' conceptions do not always coincide (Ballard *et al.* 2001, Dumit 2006, Pinder 1992, Radley and Green 1992). For example, medical professionals can label a person as having an illness, yet the sufferer may not incorporate the diagnosis into their self-concept.

Survey data suggest that most women with infertility perceive themselves as having a problem before they seek medical help (Greil *et al.* 2011b), and prior studies of infertility have assumed that self-perception precedes help-seeking (e.g. White *et al.* 2006). However, little is actually known about why half of women who meet the medical criteria for infertility do not self-identify as having a problem (although see Greil *et al.* 2010), and no studies have examined men's perceptions of their fertility, to our knowledge. Thus, we use qualitative interview data from 28 women and men who sought medical, infertility treatments to examine how these individuals make sense of the infertility process and its effects on self-definitions.

Physicians define infertility as lack of conception after 12 or more months of recurrent, unprotected intercourse (American Society for Reproductive Medicine 2008). Infertility is quite common; Boivin *et al.* (2007) estimate the global prevalence at approximately 9 per cent. In the US, about 12 per cent of childbearing aged women reported symptoms that qualify as 'impaired fecundity' in 2002 (Chandra *et al.* 2013). Lifetime prevalence rates for US women are considerably higher. The National Survey of Fertility Barriers reveals that 51.8 per cent of US women aged 25 to 45 met the medical criteria for infertility at some point in their lives (Greil *et al.* 2011b). Only about half of women meeting the medical definition of infertility, however, seek fertility treatment (Chandra *et al.* 2013).

Defining oneself as infertile usually involves negotiations between the individual and medical professionals, spouses/significant others, and, possibly, larger social networks. Yet there is still lack of clarity regarding why some people who meet criteria for infertility – and even seek medical help to conceive – do not define themselves as infertile. Infertility is not life threatening, and therefore it is not always necessary for individuals to recognize infertility to be healthy. Conceptualizing infertility as a socially constructed process reveals what is involved in the self-definition process: defining the inability to have biological children as problematic, the nature of that problem, and an appropriate course of action. In addition to increasing knowledge about the process of self-definition (or not) as infertile, the study of infertile self-perceptions contributes to broader efforts in the sociology of health and illness to understand the process of self-definition of non-life-threatening illnesses in the context of medicalized health care and professional diagnosis.

Symbolic interactionism and the dynamic self-definition

Mead (1934) conceived of the self as a malleable, continuous process emerging out of interaction with significant others through creating shared meanings. The self is reflexive with an objective aspect – the ‘me’, the reflection of the expectations and judgments of others – and a subjective aspect – the ‘I’, which responds creatively and spontaneously to the ‘me’. Symbolic interactionists utilize the term ‘identity’ either as a synonym for, or as an aspect of, self. McAdams (1997) refers to identity as being synonymous with the ‘me’, the sense we have of ourselves – the way we use the term here. Thus, we use the terms ‘identity’, ‘self-perception’, and ‘self-definition’ interchangeably.

Symbolic interactionists from various perspectives posit a process of self-confirmation, where significant others have influence over self-definition through frequent interaction and occupying positions of legitimate authority and are therefore more likely to influence change in self-perceptions (Asencio 2011, Asencio and Burke 2011). Self-definitions can also shift when external situations prevent individuals from achieving or maintaining a valued identity, which can be important sources of psychological distress (Burke 1991, Thoits 1991). In these instances, people experience identity ‘disruptions’, (DeGarmo and Kitson 1996) or ‘interruptions’, (Burke 1991, Marcussen 2006), which should be more stressful when the interruption is repeated or severe and when the self-definition in question is highly valued (Burke 1991, Thoits 1991). People will also experience higher levels of disruption if they view a new self-definition as undesirable or imposed from without (DeGarmo and Kitson 1996, Thoits 2006). People who experience identity disruptions will likely act to restore consistency between self and behavior by modifying their behavior to align with others’ expectations so as to reinforce their self-definitions. If they are unable to change their behavior, then the self-perception is likely to change to match the perceived perceptions of others (Burke 2006, Burke and Harrod 2005; Burke and Stets 2009, Miles 2014).

The emerging field of the sociology of diagnosis, which conceptualizes diagnosis as both a label and a process (Jutel 2009, Jutel and Nettleton 2011), complements the symbolic interactionist perspective. Prior research demonstrates that medical diagnoses are influenced by social, economic, and political forces. In addition, medical diagnoses validate what counts as disease, provide patients access to resources for medical help, and shape patents’ senses of self (Becker and Nachtigall 1992, Charmaz 1995). These diagnoses, however, are socially constructed and thus accepted, contested, or negotiated in the process of social interaction. Diagnostic categories are further complicated in cases similar to infertility that do not fit clearly into a dualistic conception of disease versus non-disease (Greil 1991, Jutel and Nettleton 2011, Sandelowski 1993).

Infertility and self-definition

Several scholars noted that we also choose our behaviors based on our future aspirations: we think about who we want, or do not want, to become (Loftus and Namaste 2011, McCall and Simmons 1978, Oyserman and James 2011). The repertoire of possible selves in a given society is shaped by social structure, including life course norms (Markus and Nurius 1986). Parenthood is generally a desired and anticipated role for most US women (Becker 2000; Matthews and Martin-Matthews 1986). Despite the increasing proportion of women without children (Dye 2008), most US women do not expect to be childless (Thornton and Young-DeMarco 2001), and women's social identity has remained strongly linked to the mother status (Koropeckyj-Cox *et al.* 2007), particularly biological motherhood (Ulrich and Weatherall 2000). Because most people assume that they can become parents, infertility is often experienced as a feared and unanticipated identity (Paternoster and Bushway 2009).

Some scholars have applied theories of self-process to infertility. Loftus and Andriot (2012) describe infertility as a 'failed life course transition' that leads to a 'destabilized self'. Others suggest that for infertile people who highly value parenthood, the transition to non-parenthood is both real and stressful despite the fact that no objective change in status occurs (Matthews and Martin-Matthews 1986, McQuillan *et al.* 2012). Becker (1994) reveals the chaos that people feel during the fertility treatment process, corresponding to the idea of infertility as an unanticipated 'role blockage' that leads to feelings of failure (Miall 1986, Whiteford and Gonzalez 1995) and having to manage this disrupted identity (Exley and Letherby 2001). Thus, prior studies demonstrate the value of pursuing the idea that infertility can be experienced as identity disruption.

There is an important distinction between the medical definition of infertility and individuals' self-definitions of having a fertility problem (Greil 1991). Many women who meet medical criteria for infertility do not perceive themselves as infertile and may even resist this label (Abbey *et al.* 1994, Loftus 2009). In White *et al.*'s (2006) sample, only

35 per cent of women who had met the medical criteria for infertility self-labelled as having had a fertility problem. There are several explanations for this trend. First, a lack of conception is only seen as problematic if it interferes with the fulfilment of life course goals; some women who meet the medical criteria for infertility are not actively trying to conceive (Greil *et al.* 2013). Second, some women may want to avoid a stigmatizing label (Abbey *et al.* 1994). Whereas the medical conception regards infertility as a treatable health condition, the lay understanding of the term can suggest permanence and the end of hope as many people often equate the term 'infertile' with 'forever involuntarily childless', 'barren', or 'sterile' (Loftus 2009, Miall 1994). Thus, people may resist a self-perception that they perceive as both undesirable and permanent. Third, infertility usually occurs in a couple context (Johnson and Johnson 2009), and the source of infertility can reside in multiple bodies, thus complicating the process of self-labelling as having a fertility problem. Moreover, women may not see themselves, but rather their partners, as 'infertile', or may self-identify as infertile even if they do not meet the medical criteria.

Through qualitative research, Sandelowski (1993) identified four definitions of infertility that led men and women to either accept or distance themselves from an infertile identity: (i) functional (regarding infertility as a biological incapacity to reproduce without medical assistance); (ii) behavioral (defining infertility as the activities required to become pregnant); (iii) empirical (seeing infertility as synonymous with not having a desired child); and (iv) phenomenological (seeing infertility as part of one's identity). Only the last type of definition truly affected the individual's sense of self as they internalized images of themselves as 'incapable, abnormal, defective' with a 'spoiled identity'. Yet, this internalization of an infertile self-concept is not a given, but a variable in the experience of infertility. For some women infertility might figure as a 'landmark event' (Sandelowski 1993: 65) demarcating a before and after moment in their lives. For others, infertility might be a fleeting condition that is no longer relevant once one has been 'cured' through pregnancy, adoption, or another resolution.

In keeping with symbolic interactionism, studies on infertility show that social cues from significant others can lead people to pursue medical help (Bunting and Boivin 2007, Greil *et al.* 2013) and even to self-identity as having a fertility problem. For example, Loftus (2009) observed that whether women claimed the infertility label depended to a large degree on their interactions with other infertile women in support groups.

Medical professionals may promote certain physical and mental experiences as symptoms to confer the infertile label through their interpretations of both patients' experiences and medical tests. Thus, self-definition is affected by interaction with a health professional who has the authority to assess a bodily problem and label it (Miall 1986, Olshansky 1987). This diagnosis may then become incorporated into the self and can provide a message to some that 'things will never be the same again' 'via the syntactic construction of being: I *am* [specified illness]' (Jutel 2009: 25–26). In this sense, the infertility experience has paradoxical implications for identity and identity disruption. To obtain the desired possible self – as a mother or a mother with an additional child – women often encounter situations in which medical staff have power to confer a new identity (infertile) that is inconsistent with the desired identity that would come with having a(nother) child (fertile).

The temporal connection between medical diagnosis and infertility self-perceptions, however, is far from clear cut. Some studies suggest that whereas some women perceive a problem only after receiving a diagnosis, other women self-identify as having a fertility problem after both diagnosis and treatment. In contrast, some women push for diagnosis, having already perceived a problem (Becker and Nachtigall 1992, Greil *et al.* 2011a, Johnson and Fledderjohann 2012). Why there are differences in these trends is, as of yet, unknown. Our aim in this article is to illuminate the process of identity change in relation to the experience of medical contact and treatment. From a theoretical point of view, understanding the processes that develop an 'infertile' self-definition is important to better understand the interplay between self, behavior, and social institutions and has implications for better understanding how people experience a wide range of health conditions. From a practical point of view, understanding how medical contact and treatment fit into the processes of infertility self-identification should lead to better estimates of the need for fertility services, better understanding of factors associated with infertility stigma and distress, and better strategies for communicating with people that meet criteria for infertility. Thus, the qualitative interviews in our analysis show processes of identity change as they grapple with self-labels, starting from when people suspected infertility through the diagnostic and treatment processes. We show that self-definitions are not static but shift over time as women and men interact with medical professionals.

Methods

To evaluate the process of self-identifying as infertile, we used qualitative, in-depth, interview data. Between April 2007 and March 2008, the first author interviewed 20 women and 8 men (more women volunteered for the study) from a large metropolitan area in the Midwestern US who had used, or were in the process of using, any type of fertility treatment in the five years prior to the interview. The study was approved by university review boards, and participants were recruited through university list-serves and newsletters, personal connections, community bulletin boards, and snowball sampling. All participants signed informed consent statements and have been given pseudonyms. Interviews were semi-structured using an interview guideline and conducted and digitally recorded by the first author as well as transcribed under her supervision. Interviews occurred in respondents' homes and offices, and the interviewer's office. When no other options were available, two interviews were conducted by phone, and one at the interviewer's home. Interviews lasted approximately one hour for a single individual or two hours for a couple if they were interviewed together for scheduling issues. Four couples were interviewed together, and two were interviewed separately.

Data were coded and analyzed using a grounded theory approach (Glaser and Strauss 1967), which is particularly useful to gain a better understanding of basic processes and issues that people experience and to capture them in their variable, non-stable states. As Charmaz (1990) states, the point of grounded theory is to reveal the meanings that participants give to phenomena and then for the researcher to raise analytic issues about them. Moreover, grounded theory in medical sociology particularly lends itself to symbolic interactionist interpretations (Charmaz 1990).

Data were coded line by line to identify core concepts related to medical contact and identifying oneself as having a fertility problem. The analytic process was dynamic and open to change by use of the constant comparative method (Glaser and Strauss 1967). Because all questions on the interview schedule were answered by all respondents, there was some amount of systematic and comprehensive coding based on *a priori* issues identified in the research aims of understanding people's reasons for using, and experiences with, fertility treatments. Yet given the variation in answers, in addition to supplementary answers and probes, coding was also fluid where different respondent answers, even to the same questions, belonged in different, or even multiple, categories. This process is made transparent in the manuscript through respondent quotes used for illustrative purposes. Theoretical concepts were developed through comparing respondent answers.

Characteristics of participants reflect the US subpopulation who use fertility treatments (Chandra *et al*. 2014) rather than the general US population (see Table 1). The majority of the participants are non-Hispanic white women with higher levels of education and income. Race/ ethnicity was an open-ended question – 24 self-identified as white, one as Arab, and three as Latina/o. Twenty-six were in heterosexual, and two in lesbian, relationships. Both lesbians had fertility issues and were not using fertility treatments simply due to the absence of a male partner. Treatment length spanned from several months to seven years, with the average being almost 4 years. Sixteen recipients had at least one successful pregnancy, two of these resulting in twins, one in triplets. The age of the interviewees at the time of their treatments ranged from 24–60 years old, with the average age at 33 years old.

Results

Patterns of self-identification

The interviews illuminate the nature of diagnosis as both category and process (Jutel and Nettleton 2011). They show that self-perceptions of infertility do not fit easily into neat categories of women who do or do not self-identify either pre or post-medical contact. Alignment of previous self-conceptions while simultaneously integrating new medical knowledge gained from testing and treatment created difficulty in situating oneself on the infertility self-perception continuum. Four

Table 1. Basic demographic characteristics

Pseudonym	*M/F*	*Age*[1]	*Treatment Length~*	*Live Birth*	*ID category*
Ada	F	33	< 6 months	N	Assuming the label
Bob	M	54	3.5 years (T1)	Y	Non-adopter
		60	6 months(T2)	Y	
Christine	F	41	3.5 years (T1)	Y	Assuming the label
		47	6 months (T2)	Y	
Cassandra	F	26	2 years	N	Non-adopter
Leslie	F	39	2 years	N	Assuming the label
Cary	M	40	2 years	N	Non-adopter – female factor
Cameron	F	29	< 6 months (T1)	Y	Uncertain/ Non-adopter
		32	< 6 months (T2)	Y	
Edward	M	30	1.5 years	N	Non-adopter– female factor
Ellen	F	29	1.5 years	N	Solidifying a tentative label
Ella	F	31	None	Y	Non-adopter – male factor
		34	4 years	Y	
Erin	F	29	2.5 years (T1)	Y	Uncertain
		33	6 months (T2)	N	
		35	1 attempt (T3)	N	
Ramon	M	31	2.5 years (T1)	Y	Assuming the label
		35	6 months (T2)	N	
		37	1 attempt (T3)	N	
Hillary	F	31	1 year	Y	Assuming the label
Iris	F	29	1 year	N	Assuming the label
			6 years	Y	
			None	Y	
Jaime	F	26	9 months∞	N	Non-adopter – male factor
Jalila	F	28	2 years	Y	Solidifying a tentative label
Julie	F	30	2 years∞	N	Non-adopter
Kevin	M	29	2 years∞	N	Non-adopter – female factor
Marita	F	26	6 months (T1)	Y	Assuming the label
		28	6 months (T2)	Y	
Mai	F	24	4 years	N	Assuming the label
Patty	F	33	2 years (T1)	Y	Assuming the label
		37	1 year (T2)	unknown	
Peter	M	39	1–2 years	Y	Non-adopter– female factor
Reece	F	30	4 years	N	Solidifying a tentative label
Robin	F	28	3 years	Y	Non-adopter for personal ID; Assume the label at couple level
Kirk	M	29	3 years	Y	Assuming the label
Sasha	F	35	3–4 months	Y	Assuming the label
Terry	M	30	1 year	Y	Non-adopter– female issue
			2 years	N	
Tonia	F	30	< 6 months	Y	Non-adopter
			None	Y	

Shaded coupling of rows represent partnerships.

1. Age – approximate age at onset of treatment process.

~ Treatment length numbers are rounded and approximated. The time period begins with the diagnostic process until the conclusion of treatments or time of interview if currently still in treatment and includes short waiting periods between treatments.

T1 – 'Time 1', or first round of fertility treatments.

T2 – 'Time 2', or second round of fertility treatments.

T3 – 'Time 3', or third round of fertility treatments.

∞ – treatment is ongoing.

response categories emerged for adopting a self-perception of having a fertility problem: (i) the non-adopters – never adopting the self-perception pre- or post-medical contact; (ii) uncertain – not being fully committed to the self-perception pre- or post-medical contact; (iii) assuming the label – not having prior fertility concerns but adopting the self-perception post-medical contact; and (iv) solidifying a tentative identity – not being fully committed to a self-perception pre-medical contact, but fully committed post-medical contact. Therefore, two of the categories reflect stable experiences and two reflect processes of change in self-perception through the progression of interacting with medical professionals to deal with infertility.

Non-adopters

Twelve people in this study never seemed to self-identify as having fertility problems, despite making medical contact and having themselves or their partners diagnosed with various fertility-related conditions. Three women in this category were personally diagnosed with fertility issues. Julie suspected a health issue, though not necessarily related to fertility, when she discontinued oral contraception and, in a year's time, had only four periods and pain in her right side. She first went to a family practitioner who inspected her kidney; then she consulted a gynecologist who diagnosed her with endometriosis and informed her that she had only one fallopian tube and ovary. She was extremely positive, however, and did not self-label as infertile, even after a maximum six-month course of medication, an insemination, and one round of in-vitro fertilization (IVF). Despite unsuccessfully undergoing fertility treatments for almost two years, she said she would only feel unsuccessful if she were unable to become pregnant through her other two IVF rounds covered by insurance. Thus, Julie has not yet self-labelled as being infertile because she has not utilized all of her available resources to get pregnant– thus the possibility for pregnancy still exists. The fertility diagnostic and treatment processes did not convince Julie to accept the infertile label, but an unwelcome outcome might; the implication is that only those who can never conceive, even with medical help, count as truly infertile.

Despite years of painful menstrual cycles, Cassandra did not suspect fertility problems until a physician found a large amount of endometrial tissue, yet was still reluctant to consider herself infertile:

> Reproductive Endocrinologists (REs) note that there is a connection to infertility, but don't know why. The statistic that was quoted to me was 40 per cent–50 per cent of women who have endometriosis are also infertile. But that means that 40 per cent–50 per cent of women are not.

Thus, Cassandra defined her condition as related to, but also distinct from, being infertile. Cassandra also had to integrate new with old information to understand her changing body within a medical context, which seemed to cause some cognitive dissonance. For her, the surgical removal of the endometrial tissue made her more hopeful that she was not (or no longer?) infertile: 'I was still believing that surgery would take effect, that … my body might normalize. Maybe I was fantasizing. I was hoping that things could proceed normally'.

Tonia used the rhythm method as contraception for years, yet became concerned when she stopped and was not pregnant in 4–5 months, especially given that no 'accidents' had ever happened. She went to her family doctor who recommended a gynecologist who diagnosed her with polycystic ovary syndrome (PCOS). Tonia became pregnant quickly after drug therapy. Tonia's actions strongly suggested that she did not self-label as someone with major fertility problems because she used the rhythm method again after her pregnancy and spoke with a new physician: 'I told her about the struggles I had … I asked if we would have to do the same thing if we decide to have another child and she said more than likely we will'. Tonia never had to use medications again; she got pregnant while using the rhythm method, had a second child, and is now using oral contraception.

Seven of the nine other individuals in this category were a member of a couple where the other partner was diagnosed with fertility problems. The non-diagnosed partners noted how their partners self-identified, but they did not self-identify as having a fertility problem themselves. One exception was Edward, who resisted his wife's post-diagnosis self-identification because he defined it as a lack of hope for conception:

> Ellen … got diagnosed with polycystic ovarian syndrome and … I thought, 'people with that get pregnant all the time'. Nobody has said, 'Oh, you're one of the worst cases' or 'this isn't going to work for you'. In fact they were saying 'it looks pretty good, it should be fine' so I pretty much thought it would be fine.

The other exception was Robin, who has a shorter menstrual cycle, which she viewed as something to work around that is easily fixable, but not necessarily a fertility problem. Despite this, Robin identified as having a fertility problem only at the couple, not the personal, level during the interview portion where both she and her husband were present: 'we were able to figure out what was wrong with both of us'. Perhaps Robin did this to not place all the blame on her husband, perhaps to preserve his sense of masculinity and its associated virility (Moore 2007). Yet, before her husband joined the interview, Robin revealed that the RE:

> identified right away that our problem was totally on Kirk's side … He won't admit that. But it was a big part of the problem. I wasn't producing enough progesterone; I was starting to bleed early. He felt like that part of it, we could really control using the right medication a bit better. But, he was concerned about Kirk's part.

Overall, across the range of scenarios described above, non-adopters shared certain characteristics. First, despite being diagnosed, or having a partner diagnosed, with various problems, they remained optimistic about the possibility of pregnancy in the future. Second, some viewed their problem as distinct from infertility or an easily fixed infertility problem. Third, they viewed the fertility problem as distanced from the self because their partner had the sole problem or the more concerning/difficult problem to treat medically. Thus, the infertility diagnosis was an evolving process.

Uncertain: Not fully committed to the identity pre or post-medical contact

Two women verged on being non-adopters but also considered the implications of their medical diagnoses, thus not fully committing to an infertile identity. Cameron fluctuated between being a non-adopter and identifying as having a very mild case of infertility because she was able to get pregnant, twice, after using fertility drugs for very short time periods. Cameron went to her obstetrician/gynecologist after 5 months of trying to conceive with no prior suspicions of fertility problems due to her 'impatience':

> We had no problems, a healthy sex life. He had never impregnated anyone, I had never been pregnant, but you go your whole life expecting it to be ok so I was really impatient. I had gotten off … birth control … I had been on birth control for quite some time and it took a while to get a cycle that was normal. I just kept getting my period … and I had 7 or 8 friends in that time frame that called me, 'Oh, I'm pregnant'. My heart would break every time. I luckily had an OB/GYN that … knew me well … I was very impatient, and I said, 'I'm not pregnant yet, I'm a healthy person, young, I don't understand'. So he took the steps to test me, didn't just send me on my way, and found out I wasn't ovulating.

Cameron reacted very negatively to her initial medication and decided to discontinue after the first time. Her OB/GYN re-tested her and then diagnosed her with PCOS. After 2 weeks on a different medication, Cameron was pregnant. Given that it was relatively easy to get pregnant, and Cameron 'didn't know the impact of it [PCOS]', she used contraception again. Only post-diagnosis and treatment did Cameron start reading about PCOS, which made her worry about her health in general, but she still does not fully self-identify as infertile.

Erin viewed her body differently than Cameron prior to medical contact, where her irregular menstrual cycles were signs of fertility problems. To Erin, women are naturally fertile; thus her infertile identity was strongest during the diagnostic and treatment processes:

> . . . being diagnosed with PCOS and learning what that does. . . made me feel unhealthy. Having to go through fertility treatments made me feel even more unhealthy. Because I've always thought of being pregnant and having a child as this really natural process. And … if I have to work this hard to make my body do a natural process, and it may not even work, how messed up is my body that I have to take all these pills and shots and do all these things just to ovulate, which is this totally normal bodily process for a lot of women, or is supposed to be … I've always considered myself to be a healthy person so that was hard.

Both Erin and her husband were diagnosed with fertility issues, and underwent high-tech treatments that led to conceiving a child. Later, Erin had a liver mass removed and then her cycles became regular. Erin both distrusted medical diagnoses and believed that infertility was a label best applied to a permanent condition. Thus, she questioned her status as 'infertile' as her body changed over time:

> I always had irregular cycles. My sister is the same … and a doctor … told her that she might not be able to have kids. That always was in my head, but at the same rate you always hear of things happening. Just because a doctor says something, doesn't mean that [it] will happen … Now I have regular cycles, it's confusing to me. Do I still have that, or has my body changed? I thought that once you have it, you have it.

Both Erin and Cameron initially perceived themselves as 'healthy' people and had to reconcile that initial self-perception with new information after their medical diagnoses and treatments. While neither appeared to fully move into a new identity as 'infertile', Cameron in particular refused that label because of its presumed permanence. Both women took on the new status of being someone with a diagnosed health condition –more specifically, a health condition that had implications for their fertility.

Assuming the label: took on identity post-medical contact

The 'assuming the label' category was the largest, containing 12 people who did not have fertility concerns prior to pregnancy attempts. Only after attempting to conceive did they have some concerns (but did not self-identify) and sought medical help. Some had successful pregnancies, others did not. Interestingly, the two men in the study who were diagnosed with fertility problems addressed their identities in relation to their wives' emotional well-being and accepted responsibility. This is contrary to Webb and Daniluk's (1999) findings that men diagnosed with infertility issues tend to avoid the diagnostic label and its attached stigma by tacitly blaming their wives for the couple's infertility issues. In essence, the men in this study were not denying their roles in the fertility process in addressing the potential stigma and guilt that women feel with infertility.

Although Ramon's wife was diagnosed with PCOS, Ramon blamed himself for their fertility issues and addressed his share of responsibility in reference to his wife: 'I was glad that I had something. She was blaming herself more than anything else'. Kirk makes similar statements, yet also thinks about his diagnosis on a pragmatic, treatment level:

> In the beginning, I was glad it was a problem with me. My brain was thinking that it was easier to treat me than her. I don't know why. In reality it's the opposite. It's harder to treat men. Part of it was my own stress. I can deal with it. I don't want her to have to deal with the stress of feeling that something is wrong with her.

In reference to the scope of fertility treatments, however, Kirk and his wife did not have to use very involved treatments in order to become pregnant with twins.

The women in this category are very diverse in terms of treatment decisions (low-tech/simple drugs v. more intensive options) and fertility outcomes (failure to conceive, adoption, pregnancy with multiples, unexpected pregnancies, etc.), yet vary in their adoption of self-labels. For example, Iris did not suspect prior infertility due to past, 'normal' annual exams, yet after trying medication, inseminations, and IVF, it was a discussion of further testing that solidified her feeling of being terminally infertile:

> I remember the day they called. They were re-testing my level and said, 'I'm so sorry'. Like a death. I knew that meant I wasn't going to have children … everything came crashing down. I couldn't believe it was happening to us, to me.

Marita also did not suspect infertility before attempting conception, despite years of menstrual issues. Similar to Iris, getting a solid diagnosis, in this case PCOS, affected Marita's self-label:

> It was awful, there was finally this name to it. I have this thing and this thing is not good … They have pamphlets for in the doctor's office. If you Google it there's a lot of bad things that can come from it. It will just be a constant.

Other women had 'issues' that could have been interpreted as fertility problems, but were not interpreted as such until receiving actual diagnoses. For example, although Christine was 41 years old, she did not suspect fertility problems and tried to self-inseminate with donor sperm (her husband had had a vasectomy) shipped to her home for two years. She only consulted an RE after a conversation with a friend who discussed her own fertility issues. The RE told Christine that her eggs were too old. After that, Christine and her husband fully accepted everything the RE suggested. They went through extensive high-tech treatments, twice, for two successful pregnancies.

Robin's identification as having a fertility problem existed not at the personal, but at the couple level; she used the term 'we' to discuss the problem. Similar to the above examples, Robin did not initially suspect fertility problems. She knew her cycle was short and discussed it with her family practitioner, who gave her inaccurate advice about early ovulation. After a year of trying to conceive, Robin and her husband, Kirk, returned to the family practitioner who performed tests and found that Robin ovulates later than she thought and that Kirk's sperm motility was very low. A urologist retested Kirk and gave him Clomid. When Robin went to her annual pelvic exam, she discussed these issues with her gynecologist. The gynecologist's referral to a specialist was what led Robin to self-label as having fertility problems:

> I remember it being probably one of the worst days of my life. We went in … and I was explaining to him my problem … how [Kirk] had been given this Clomid, but nobody was trying to figure it out … our results. He told me, 'I can't help you'. He gave me a referral to the reproductive endocrinologist. That was horrible, because, suddenly it was like, 'Oh, we really do have a problem'.

Robin and Kirk did not receive any new diagnoses from the RE, but the confirmation from a specialist solidified Robin's self-label: 'It isn't because we couldn't figure it out. It's hard to accept that we had a problem, but it was liberating. We learned that we really did need help'.

The main commonality across members of this group was that the process of going in for medical consultation and having a diagnostic label conferred by a specialist, transformed initial health 'concerns' into a new status of the self as infertile. Many of the women spoke of it as a sort of epiphany moment: receiving the phone call, finally having a name for their condition, or suddenly realizing, as Robin said, 'we really do have a problem'. This echoes Sandelowski's (1993) work, where some defined infertility as a 'landmark event', marking the moment of realization as a demarcation between two statuses: before the diagnosis and after.

The last respondent differed from the others; she believed that the fertility treatment, not the diagnosis, created severe depression that made her embrace an infertile label; one that meant that her body was functioning abnormally. Patty was deemed healthy after a general physical by a family practitioner, so she and her gynecologist did not think she would encounter difficulties getting pregnant through donor sperm insemination (due to the lack of a male partner). She endured a few years of failed attempts, starting medication about halfway through. Her statements reflect her self-label as having a fertility problem becoming quite acute due to the medication:

> I started [journals] when my mental attitude started sliding downwards ... I was talking with people about things that were inappropriate. I can't apologize for who I was then. That wasn't me. I was on major hormone-changing drugs. I had no control over my body, and I did feel like my body was failing me. It was like, 'Ya know, I was not meant to be a mother. Why am I going through this?' ... all these things were going through my head. I have pictures ... that I drew. There's this stick figure, and there's this big, empty circle where my uterus is supposed to be and it's scratched out. It's this ... big void in my body that doesn't function.

Solidifying a tentative label: not fully committed pre but fully committed post-medical contact

Three women had suspicions about their fertility based on menstrual issues prior to attempting to conceive. Ellen's PCOS diagnosis confirmed her identity as infertile. Because of this identity and unsuccessful fertility treatments, she discontinued birth control and had an unintended pregnancy a few months after adopting a baby (yet still identifies as having a fertility problem).

Reece did not initially suspect fertility issues; however, she began experiencing health issues, some related to menstruation, and believed that her medical training as a radiologist gave her medical knowledge that led her to suspect potential fertility issues. When she sought medical help, several physicians dismissed her concerns, and despite her discomfort, she followed their advice and did not necessarily identify as infertile. She finally received a diagnosis of Graves' Disease (an autoimmune disorder) and was relieved to understand her symptoms: 'At this point it's not totally freaking me out; I just wanted to know what was wrong. I was glad they got the diagnosis … it made sense'.

Graves' Disease does not necessarily affect fertility, thus, Reece's self-identity changed only after several fertility related-diagnoses, a failed IVF attempt (and marriage), and surgeries that left a mismatched ovary and fallopian tube (one on the left side, the other on the right). These led her to view her body differently, feeling infertile and unfeminine:

> … both Graves' and endometriosis, depending on what you read, are auto-immune. Your body is fighting against your body so I did feel like it was rebelling against me and certainly in the situation I am in … Being divorced and thinking of meeting someone and having a marriage I feel like, in terms of femininity, that has changed. My husband, he's been through that process, he knows what I was before and after and I think starting fresh with somebody … I wonder if some man would want to select a woman who can't bear children to be their spouse.

Jalila used donor sperm inseminations due to the lack of a male partner and had suspicions about her own fertility without fully self-diagnosing. She initially spoke with friends, then sought professional help, yet still was uneasy about a solid diagnosis:

> I did suspect some substantial fertility issues. I hadn't had a regular period since I was fifteen … something was going on I just didn't know what. PCOS is common infertility among Saudi woman and really many women … I went to many women friends first. My gynecologist was not terribly helpful and pretty dismissive of PCOS as a diagnosis. I felt like all of those things were going on for me but it didn't feel legitimate to call this a diagnosis. It's a syndrome, so it's a collection of issues sort of grouped together.

Yet after several unsuccessful inseminations, Jalila seemed to assume the infertile label, which corresponded with an idea that her body was not working properly. Whereas Reece's statement reflected an internalization of the idea of motherhood and femininity, Jalila discusses her internal struggles with the same ideas:

> I was talking to my good friend and saying my body was broken and … I felt like I was losing myself in some way because I don't believe a woman's worth is determined by whether she can produce children. So what does that mean about me, what am I saying? It was weird … I felt like 'oh I have internalized these shitty values that I completely disagree with and what does that mean as a feminist?'

Interestingly, the shift in psychosocial identity from uncertainty to thinking of herself as infertile also made Jalila feel like her medical status could shift and gave her a sense of urgency: 'I was worried that my fertility was going to erode more'.

The women in this group differed from those in the 'assuming the label' group in that their interviews suggest that they were looking for a diagnosis and pushing for medicalization (Becker and Nachtigall 1992) to confirm their own suspicions about their health and fertility. Thus, for these women, the diagnosis of infertility was not an epiphany moment like those above, but rather one moment in a more chronic process to define a/an (increasingly) problematic body. At the same time, this did not mean that infertility was any less disruptive to their lives. Indeed, among other things, both Reece and Jalila saw their unruly bodies as a threat to their internalized values of being a woman/being feminine (Becker 2000).

Discussion

A noteworthy finding from the qualitative interviews is the importance of identity disruptions. Several scholars (Burke 1991, Thoits 1991) noted that identity disruptions should be more stressful when they are repeated or severe, when the identity in question is highly valued, and when people view a new identity as undesirable or externally imposed (DeGarmo and Kitson 1996, Thoits 2006). Thus, many people in our study who wanted to be biological parents had their identities disrupted when they were informed that they had fertility problems by medical authorities. How they made sense of this disruption, however, varied greatly.

Prior research has not provided a clear description of the connections between medical diagnoses and self-perceptions as infertile. The in-depth interview data presented here add to the larger body of work by documenting people with similar objective medical situations who have different subjective experiences of their inability to conceive 'naturally' and the degree to which they do or do not embrace the medical label 'infertile'. Participants' comments about fertility diagnoses and treatments indicate diversity with regard to self-labelling as infertile. Similar to Sandelowski's (1993) finding that men and women will either distance themselves from, or accept, infertile identities depending upon how they define their situation, we find that infertile patients differ in the logics they use to embrace or reject the diagnosis. Some decided that a diagnosis of a specific problem meant that they were infertile; others saw diagnosis as a path to a child and therefore a way to avoid a self-definition. Some patients presumed that treatment to get pregnant indicated that they really were infertile; whereas others decided that if they could get pregnant– even with medical treatment – then they must not really be infertile.

Although most of the participants had at least some concerns about their or their partners' fertility that led to medical help-seeking, the quotes above reflect considerable variation in people's reflections on pregnancy challenges. There were no clear patterns that explained why some did and some did not self-label. Self-labelling (or not) was *not* associated with age, type of diagnosis, ability to achieve a pregnancy through low or high-tech fertility treatments, experiencing an unexpected pregnancy, or having prior menstrual issues. Thus, even when women suspect a problem and even when there is an indication of a problem, self-labelling does not necessarily occur, sometimes because women/couples can still imagine the possibility of pregnancy.

Our data also reveal that many people shifted their fertility identities as they progressed through the diagnostic process. This may be due to the need for continuity after biographical disruptions (Becker 1994), yet our quotes highlight the relevance of medical contact in these processes. Comparable to a quantitative study (Greil *et al.* 2011b), the majority of the individuals changed their identities post-medical diagnoses when someone with the power to label said there was a problem. Our qualitative data, however, reveal that there was variation in those who fully identified post-diagnosis – some individuals suspected fertility problems and then made medical contact whereas others made medical contact and subsequently self-identified. Thus, interactions between women, partners, and doctors, in addition to the varied meanings of diagnoses and treatments, contribute to constructions of an identity as someone with a fertility problem. The participants in our interviews all met the medical criteria for infertility and had contact with medical professionals. Therefore, medical institutions may function as proximate social structures (Merolla *et al*. 2012) that facilitate the process of identity change to infertile.

Medical contact, however, did not always affect self-identification; some people in the sample received fertility treatments but never self-labelled as having a fertility problem. This echoes previous research that finds that some women with fertility problems think of themselves as infertile and others do not (Greil 1991, Loftus 2009), yet previous research has not thoroughly examined why these differences exist. Moreover, two women in our sample seemed uncertain– they identified more strongly as someone with a fertility problem at certain points during their diagnoses and treatments, suggesting that self-labelling as someone with a fertility problem can respond to on-going interactions with medical professionals and therefore is not a permanent state for all people, which reflects diagnosis as a situational process (Jutel and Nettleton 2011). Rather, consistent with symbolic interactionism, self-labelling is shaped and reshaped through the process of interpreting information about the situation (e.g. diagnoses, treatments, achieving or not achieving pregnancy) and interactions with significant others, including medical professionals.

Our data also speak to prior research on the sociology of diagnosis, showing the complexity of coming to terms with/internalizing an infertility diagnosis. Whereas diagnosis can be a beginning point from which people make sense of their symptoms, it does not always have to be. Many women in this study came to their diagnostic appointments with pre-conceived notions of fertility. Thus, diagnosis was more a beginning point of negotiation about the definition of the situation, showing diagnosis should be viewed as a as a process (Jutel and Nettleton 2011). Diagnosis also referred to a category, but not necessarily one that medical professionals utilize. Applying diagnostic categories to oneself became complicated because many of these women located themselves in non-medical categories that were ‘in-between’ categories such as ‘not yet pregnant’ (Greil 1991) rather than ‘infertile’. We also saw complications arise with defining infertility within the couple context, where some couples agreed upon labelling one, or both, partners, and others did not, which suggests the need for future research into infertility self-perceptions and couple dynamics.

Our data may also reflect the possible precarious situation of certain diagnoses as forms of medicalization, where unacceptable social conditions (such as involuntary childlessness), are given medical diagnoses with proposed medical solutions. Thus, whether or not one fully embraces a medical diagnosis may affect his/her choices about future treatment options. Physicians may take for granted the utility of the simple diagnostic label 'infertile', without realizing that the label has many social meanings that patients may embrace as a route to treatment, deny as a hopeless situation, ignore, or be tentative about. Thus, physicians may need to adopt varying strategies for communicating with people who meet criteria for infertility as this may change their treatment recommendations. Yet, study participants also describe considerable agency in the process of diagnosis, despite the power asymmetry in most medical encounters such that providers have more power than patients (Conrad 1992, Jutel and Nettleton 2011). Overall, our data reveal the mutability and complexity of the provider–patient diagnostic labelling process.

As with all research, our data have limitations. Ideally, longitudinal interviews would have better captured the process of identity construction, yet we had to rely upon participant recall for most of the interviews. Only two participants were undergoing treatment at the time of the interview, yet all participants had used treatments within the past 5 years of the interview. Additionally, we were unable to discern potential gender differences in the process of self-labelling because the sample contained more than twice as many women as men, a common issue with reproductive research. It is possible, however, that men and women have different experiences of self-labelling *vis-_a-vis* medical contact because of the highly gendered construction of infertility by the medical industry and greater society (Culley *et al.* 2013). Finding ways to engage more men in infertility research is a valuable future avenue of research. Our small sample did not provide evidence of systematic variation in self-labelling by social location, yet social constructions of (in)fertility related to race/ethnicity, social class, socio-political context, ability, and sexual orientation suggest that a larger study could provide important information on subgroup experiences of infertility. Last, future research should explore using more explicit questions about the meaning of the term 'infertile' among lay compared to medically trained populations.

Even with limitations, we provide insights regarding different ways of making sense of infertility diagnoses. Consistent with symbolic interactionist perspectives on self-labelling, we find that only some participants view themselves as someone with a fertility problem. In addition, even when medical professionals convey a medical diagnosis, only some patients embrace the diagnosis in their self-label. Our findings suggest that medical professionals may need to better articulate what a diagnosis means to patients, and patients may want to ask for more clarification from medical professionals. Social scientists also need to recognize the variations in meanings patients attribute to diagnosis and continue to study diagnosis as both a category and a process (Jutel and Nettleton 2011).

Our findings may also suggest that self-labelling as having a health issue and making medical contact are dialectically associated, particularly for conditions where treatment is discretionary (e.g. incontinence, erectile dysfunction, social anxiety, and baldness) and for understanding other social situations where the temporal relationship between self-concept and behavior is problematic, such as delinquency, criminal desistance, career change, and weight loss. Moreover, our findings have implications for identity change as related to feared identities or other instances of role blockage, such as the death of a spouse, failure in school, incarceration, unemployment, and chronic illness.

References

Abbey, A., Andrews, F.M. and Halman, L.J. (1994) Psychological predictors of life quality: how are they affected by infertility, gender, and parenthood?, *Journal of Family Issues*, 15, 2, 253–71.

American Society for Reproductive Medicine. (2008) Definitions of infertility and recurrent pregnancy loss, *Fertility and Sterility*, 90, S60.

Asencio, E.K. (2011) Familiarity, legitimation, and frequency: the influence of others on the criminal self-view, *Sociological Inquiry*, 81, 1, 34–52.

Asencio, E.K. and Burke, P.J. (2011) Does incarceration change the criminal identity? A synthesis of the labeling and identity theory perspectives on identity change, *Sociological Perspectives*, 81, 2, 163–82.

Ballard, K.D., Kuh, D.J. and Wadsworth, M.E.J. (2001) The role of menopause in women's experiences of the 'change of life', *Sociology of Health & Illness*, 23, 397–424.

Becker, G. (1994) Metaphors in disrupted lives: infertility and cultural constructions of continuity, *Medical Anthropology*, 8, 1, 383–410.

Becker, G. (2000) *The Elusive Embryo: How Women and Men Approach the New Reproductive Technologies*. Berkeley: University of California Press.

Becker, G. and Nachtigall, R.D. (1992) Eager for medicalisation: the social production of infertility as a disease, *Sociology of Health & Illness*, 14, 4, 456–71.

Boivin, J., Bunting, L., Collins, J.A. and Nygren, K.G. (2007) International estimates of infertility prevalence and treatment-seeking: potential need and demand for infertility medical care, *Human Reproduction*, 22, 6, 1506–12.

Bunting, L. and Boivin, J. (2007) Decision-making about seeking medical advice in an internet sample of women trying to get pregnant, *Human Reproduction*, 22, 6, 1662–8.

Burke, P.J. (1991) Identity processes and social stress, *American Sociological Review*, 56, 836–49.

Burke, P.J. (2006) Identity change, *Social Psychology Quarterly*, 69, 1, 81–96.

Burke, P.J. and Harrod, M.M. (2005) Too much of a good thing?, *Social Psychology Quarterly*, 68, 4, 359–74.

Burke, P.J. and Stets, J.E. (2009) *Identity Theory*. Oxford: Oxford University Press.

Bury, M.R. (1982) Chronic illness as a biographical disruption, *Sociology of Health & Illness*, 4, 2, 167–82.

Bury, M.R. (1991) The sociology of chronic illness: a review of research and prospects, *Sociology of Health & Illness*, 13, 451–68.

Chandra, A., Copen, C.E. and Stephen, E.H. (2013) *Infertility and impaired fecundity in the United States, 1982–2010: Data from the National Survey of Family Growth*. National Health Statistics Reports 67. National Center for Health Statistics.

Chandra, A., Copen, C.E. and Stephen, E.H. (2014). *Infertility service use in the United States: Data from the National Survey of Family Growth, 1982–2010*. National Health Statistics Reports 73. National Center for Health Statistics.

Charmaz, K. (1990) Discovering' chronic illness: Using grounded theory, *Social Science and Medicine*, 30, 11, 1161–72.

Charmaz, K. (1995) The body, identity, and self: Adapting to impairment, *The Sociological Quarterly*, 36, 4, 657–80.

Chrisman, N. (1977) The health-seeking process: An approach to the natural history of illness, *Culture, Medicine, and Psychiatry*, 1, 4, 351–77.

Conrad, P. (1992) Medicalization and social control, *Annual Review of Sociology*, 18, 209–32.

Conrad, P. and Barker, K.K. (2010) The social construction of illness: Key insights and policy implications, *Journal of Health and Social Behavior*, 51, Suppl, S67–9.

Culley, L., Hudson, N. and Lohan, M. (2013) Where are all the men? The marginalization of men in social scientific research on infertility, *Reproductive BioMedicine Online*, 27, 3, 225–35.

DeGarmo, D.S. and Kitson, G.C. (1996) Identity relevance and disruption as predictors of psychological distress for widowed and divorced women, *Journal of Marriage and the Family*, 58, 4, 983–98.

Dumit, J. (2006) Illness you have to fight to get: Facts and forces in emergent, uncertain illnesses, *Social Science and Medicine*, 62, 577–90.

Dye, J. L. (2008) *Fertility of American women: 2006. Current Population Reports*. Washington: U.S. Census Bureau.

Exley, C. and Letherby, G. (2001) Managing a disrupted life-course: Issues of identity and emotion work, *Health*, 5, 1, 112–32.

Glaser, B. and Strauss, A. (1967) *The discovery of grounded theory*. Chicago: Aldine.

Greil, A.L. (1991) *Not yet pregnant: Infertile couples in contemporary America*. New Brunswick: Rutgers University Press.

Greil, A.L., Johnson, K.M., McQuillan, J. and Shreffler, K.M. (2013) The importance of social cues for medical help-seeking: The case of infertility, *Social Inquiry*, 83, 2, 209–37.

Greil, A.L., Leyser-Whalen, O., Lowry, M., McQuillan, J., *et al.* (2011a) Infertility treatment and self-identity as someone with a fertility problem: A longitudinal analysis of a population-based sample of U.S. women. Presented at the annual meeting of the Midwest Sociological Society.

Greil, A.L., McQuillan, J., Johnson, K.M., Slauson-Blevins, K.S., *et al.* (2010) The hidden infertile: Infertile women without pregnancy intent in the United States, *Fertility & Sterility*, 93, 6, 2080–3.

Greil, A.L., Slauson-Blevins, K.S. and McQuillan, J. (2011b) The social construction of infertility, *Sociology Compass*, 5, 8, 736–46.

Johnson, K.M. and Fledderjohann, J. (2012) Revisiting 'her' infertility: Medicalized embodiment, self–identification and distress, *Social Science & Medicine*, 75, 5, 883–91.

Johnson, K.M. and Johnson, D.R. (2009) Partnered decisions? U.S. couples and medical help-seeking for infertility, *Family Relations*, 58, 4, 431–44.

Jutel, A. (2009) Sociology of diagnosis: A preliminary review, *Sociology of Health & Illness*, 31, 2, 278–99.

Jutel, A. and Nettleton, S. (2011) Towards a sociology of diagnosis: Reflections and opportunities, *Social Science and Medicine*, 73, 6, 793–800.

Koropeckyj-Cox, T., Romano, V.R. and Moras, A. (2007) Through the lenses of gender, race, and class: students' perceptions of childless/childfree individuals and couples, *Sex Roles*, 56, 7/8, 415–28.

Loftus, J. (2009) 'Oh, no, I'm not infertile': Culture, support groups, and the infertile identity, *Sociological Focus*, 42, 4, 394–415.

Loftus, J. and Andriot, A.L. (2012) 'That's what makes a woman': Infertility and coping with a failed life course transition, *Sociological Spectrum*, 32, 3, 226–43.

Loftus, J. and Namaste, P. (2011) Expectant mothers: Women's infertility and the potential identity of biological motherhood, *Qualitative Sociological Review*, 7, 1, 36–54.

Mabry, J.H. (1964) Lay concepts of etiology, *Journal of Chronic Disease*, 17, 4, 371–86.

McAdams, D.P. (1997) The case for unity in the (post) modern self: a modest proposal. In Ashmore, R.D. and Jussim, L. (eds.) *Self and identity: Fundamental issues*. New York: Oxford University Press.

Marcussen, K. (2006) Identities, self-esteem, and psychological distress: an application of identity-discrepancy theory, *Sociological Perspectives*, 49, 1, 289–312.

Markus, H. and Nurius, P. (1986) Possible selves, *American Psychologist*, 41, 9, 954–69.

Matthews, R. and Martin-Matthews, A. (1986) Infertility and involuntary childlessness: the transition to nonparenthood, *Journal of Marriage and the Family*, 48, 3, 641–9.

McCall, G.J. and Simmons, J.L. (1978) *Identities and Interaction: An Examination of Human Associations in Everyday Life*. New York: Free Press.

McQuillan, J., Greil, A.L., Shreffler, K.M., Hill, P.W., *et al.* (2012) Does the reason matter? Variations in childlessness concerns among U.S. Women, *Journal of Marriage and Family*, 74, 5, 1166–81.

Mead, G.H. (1934) *Mind, Self, and Society*. Chicago: University of Chicago Press.

Merolla, D.M., Serpe, R.T., Stryker, S. and Schultz, P.W. (2012) Structural precursors to identity processes: The role of proximate social structures, *Social Psychology Quarterly*, 75, 9, 149–72.

Miall, C.E. (1986) The stigma of involuntary childlessness, *Social Problems*, 33, 4, 268–82.

Miall, C.E. (1994) Community constructs of involuntary childlessness: sympathy, stigma, and social support, *The Canadian Review of Sociology and Anthropology*, 31, 4, 392–421.

Miles, A. (2014) Addressing the problem of cultural anchoring: An identity-based model of culture in action, *Social Psychology Quarterly*, 77, 6, 210–27.

Moore, L.J. (2007) *Sperm counts, overcome by man's most precious fluid*. New York: University Press.

Olshansky, E.F. (1987) Identity of self as infertile: An example of theory-generating research, *Advances in Nursing Science*, 9, 2, 54–63.

Oyserman, D. and James, L. (2011) Possible identities. In Schwartz, S.J., Luyckx, K. and Vignoles, V.L. (eds.) *Handbook of Identity Theory and Research*. New York: Springer.

Paternoster, R. and Bushway, S. (2009) Desistance and the 'feared self': Toward an identity theory of criminal desistance, *The Journal of Criminal Law and Criminology*, 99, 4, 1103–56.

Pierret, J. (2003) The illness experience: State of knowledge and perspectives for research, *Sociology of Health & Illness*, 25, 4–22.

Pinder, R. (1992) Coherence and incoherence: doctors' and patients' perspectives on the diagnosis of Parkinson's Disease, *Sociology of Health & Illness*, 14, 1–22.

Radley, A. and Green, R. (1987) Illness as adjustment: A methodology and conceptual framework, *Sociology of Health & Illness*, 9, 179–207.

Sandelowski, M. (1993) *With Child in Mind: Studies of the Personal Encounter with Infertility*. Philadelphia: University of Pennsylvania Press.

Strauss, A.C. and Glaser, B.G. (1975) *Chronic Illness and the Quality of Life*. Menlo Park, CA: Cummings.

Thoits, P.A. (1991) On merging identity theory and stress research, *Social Psychology Quarterly*, 54, 2, 101–12.

Thoits, P.A. (2006) Personal agency in the stress process, *Journal of Health and Social Behavior*, 47, 4, 309–23.

Thornton, A. and Young-DeMarco, L. (2001) Four decades of trends in attitudes toward family issues in the United States: The 1960s through the 1990s, *Journal of Marriage and the Family*, 62, 4, 1009–38.

Ulrich, M. and Weatherall, A. (2000) Motherhood and infertility: Viewing motherhood through the lenses of infertility, *Feminism & Psychology*, 10, 3, 323–36.

Webb, R.E. and Daniluk, J.C. (1999) The end of the line: Infertile men's experiences of being unable to produce a child, *Men and Masculinities*, 2, 6–25.

White, L., McQuillan, J., Greil, A.L. and Johnson, D.R. (2006) Infertility: Testing a help–seeking model, *Social Science and Medicine*, 62, 4, 1031–41.

Whiteford, L.M. and Gonzalez, L. (1995) Stigma: The hidden burden of infertility, *Social Science and Medicine*, 40, 1, 27–36.

Williams, S.J. (2000) Chronic illness as a biographical disruption or biographical disruption as a chronic illness, *Sociology of Health & Illness*, 22, 1, 40–67.