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# Not Infertile, Can't Have Children: Non- Reproductive Health Barriers to a Wanted Child

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NOT INFERTILE, CAN'T HAVE CHILDREN:  
NON-REPRODUCTIVE HEALTH BARRIERS TO A WANTED CHILD

by

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NOT INFERTILE, CAN'T HAVE CHILDREN:  
NON-REPRODUCTIVE HEALTH BARRIERS TO A WANTED CHILD

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University of Nebraska, 2017

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Non-reproductive health barriers to a wanted baby are an understudied population in the field of infertility research. This is a concern for fertility, public health, and family scholars as the lack of information can have affects the attitudes, knowledge, and behaviors of couples with non-reproductive health barriers. Using the National Survey of Fertility Barriers (NSFB) and Survey Driven Narrative Construction, I was able to identify thirty-two women and their partners who have confronted a non-reproductive health barrier. These women did not self-identify and were grouped as such by the author. I found that the majority of the couples do not identify as infertile and do not group themselves as such. Additionally, I identified evidence of biographical disruption including the tension between having and raising children, reassessment of one's biography and identity, and coping with the disruption of illness and the related inability to have a wanted child.

## **Introduction**

Couples are often subjected to the 'nuclear' family structure in the media (Parry, 2005). The accompanying pressures of implicit pronatalist policies, such as personal tax exemptions for dependents in the United States, influence the fertility rates of a nation and reinforce that having and raising children are a substantial part of women's roles in society (Whittington et al, 1990). This perceived natural progression of marriage and children in the life course places couples in a position of having to proceed onto medical interventions when they cannot meet the idealized family type (Ulrich & Weatherall, 2000, Parry, 2005). This is largely due to current social norms, which tell us that womanhood and motherhood are essentially one and the same, and infertility is essentially equivalent to failure (Ulrich & Weatherall, 2000). This norm of motherhood is often applied to all, even though it is not always easily fulfilled. Infertility scholars have long challenged the idea that all women can have children. Furthermore, little research has explored the idea that not all women have the option of further pursuing a wanted child due to preexisting mental or physical health condition of their own or their partner. The health situation of these women and their partners is often unexpected and unplanned, and the inability to have a wanted child is a consequence of the disease and its effects. This state of sub-fecundity is commonly thought of as infertility.

The health condition and its accompanying infertility has been argued as a public health concern (Macaluso et al, 2010), however, may not include women and men who have a disease or illness which precludes having a wanted child. There has been little research on how women with non-reproductive health conditions and their partners cope with not having a wanted child. Additionally, little research has looked at how diffusion

of information on treatment options, adoption, and childfree living affects the attitudes, knowledge, and behaviors of couples with non-reproductive health barriers to a wanted child (Macaluso et al, 2010). Furthermore, the potential to spur research into the early detection and treatment of disease which may hinder future fertility has great potential to mitigate possible negative psychological effects of diagnosis (Macaluso et al, 2010).

Infertility research is traditionally designed to focus on women who have attempted, via unprotected sex for a period of twelve months (CDC, 2016), to conceive a pregnancy. Research on infertility often takes place in infertility clinics and prevents those who are not eligible for assisted reproductive technology (ART) from being observed, including those who are not able to carry a pregnancy without life-threatening consequences (Henning et al, 2002; White et al, 2006; Greil et al, 2010). Moreover, when examining non-reproductive health conditions and infertility, much of the existing research is focused on preserving fertility before, during, and after chemotherapy or other gonadotoxic therapies (Tschudin & Bitzer, 2009; Nahata et al, 2016). Due to the way infertility has been defined and studied, women with non-reproductive health conditions preventing a wanted child often do not fall neatly into a category of either a conventional fertility barrier (e.g. sterilization, reproductive conditions) or a situational barrier (e.g. lack of partner).

The women who do not fit neatly into the current categories of fertility barriers do not always have the same options at their disposal as women with conventional infertility (i.e. ART, adoption). Therefore, there is a systemic loss of the subpopulation of women who are not conventionally or situationally infertile, but still cannot have a child they desire. The unintentional invisibility of this subpopulation of women is an important gap

in prior infertility research. For example, little is known about the emotional consequences that these women and their partners face when they are physically capable of becoming pregnant but have been advised to not have a child. To create visibility for this subpopulation, I have chosen the label *non-reproductive health barrier* (NRHB) to pregnancy. My research explores how women who cannot have a wanted child because of a non-reproductive health barrier define and experience their situation.

### **Non-Reproductive Health Barriers to Fertility**

Originally considered a social problem, the inability to have a child was referred to as involuntary childlessness in prior research as late as the 1960s and 1970s (Becker & Nachtigall, 1992). With the advent of assisted reproductive technologies (ART), however, medical professionals assumed power over the definition, diagnosis, and treatment of involuntary childlessness (Conrad & Schneider, 1980; Becker & Nachtigall, 1992; Greil & McQuillan, 2010). For most women, involuntary childlessness has now become medicalized under the biomedical model, moving away from the previous social problem definition, and redefining it as the medical diagnosis ‘infertility’.

The women with non-reproductive health barriers to fertility do not necessarily fit the definition of infertility, “*a disease of the reproductive system defined by the failure to achieve a clinical pregnancy after 12 months or more of regular unprotected sexual intercourse*” (CDC, 2016; WHO, 2016). For instance, though a heart condition is a risk factor for infertility, it does not necessarily *prevent* a clinical pregnancy from taking place despite the potential serious health risks to the mother or fetus. Furthermore, the World Health Organization (WHO) describes both primary and secondary infertility in a slightly different manner. In order to be diagnosed with primary infertility WHO states that “a

woman is unable to ever bear a child, either due to the *inability to become pregnant or the inability to carry a pregnancy to a live birth*". For a diagnosis of secondary infertility, WHO states "a woman is unable to bear a child, *either due to the inability to become pregnant or the inability to carry a pregnancy to a live birth following either a previous pregnancy or a previous ability to carry a pregnancy to a live birth*". Women with a non-reproductive health barrier might either choose or be advised to avoid pregnancy due to health risks to the mother or the potential child, but not necessarily be *unable* to become pregnant.

The medicalized definition of infertility means little, however, unless the woman and/or couple actually desire the social role of 'parent' (Greil et al, 2011). Self-definition as infertile stems from the inability to be able to fulfill this desired social role, and being able to seek treatment is one additional key in the process of self-defining (Whit et al, 2006; Greil et al, 2011). Women who desire a child yet are unable to have one due to a non-reproductive health barrier have the desire to become pregnant, but lack the physical or mental health, social support, and material resources that allows the conventionally infertile to pursue pregnancy. This separates them from what research has called 'treatment seekers' (Greil et al, 2011). Although both groups face a disruption in their trajectories, the disruptions could be handled very differently.

## **Biographical Disruption**

Many women come of age with the expectation that pregnancies will occur and result in live births when they desire them (Oakley et al, 1984), and the inability to do so can be detrimental to the life course. Moreover, being diagnosed with a chronic condition is likely to have a negative impact on an expected life course, cause doubt in one's self worth, and could develop into one's master status (Becker, 1963; Charmaz, 1983; Exley & Leatherby, 2001). Chronic illness can affect social interaction through a loss of confidence in the body's capabilities, which are exacerbated by the loss of the ability to have a healthy and safe pregnancy (Bury, 1991). Furthermore, those who identify as infertile, as opposed to just not being able to have a child, might see the inability as an additional chronic illness to be dealt with. Management of multiple chronic illnesses can pose unique problems. There are factors that affect management of just a single illness (i.e. depression, fatigue, poor communication with physicians, lack of family support) which are compounded by a second illness (Jerant et al, 2005, Lindsay, 2009).

Additionally, patients will prioritize as important different illnesses even when identical illness sets (e.g. heart disease and infertility) are experienced. Often, the illness that is most urgent and has the potential to cause the most disruptions in daily life is the first priority (Lindsay, 2009). Dependent on social context, age, as well as barriers to treatment and adoption, it could be that infertility is ignored to minimize disruption of one's life or that the infertility eclipses other chronic illnesses due to the desire for a child.

Chronic illness carries with it two meanings of the illness, the consequences and the significance (Bury, 1991). Consequences are the disruptions of day-to-day life,



whereas the significance is the variance of how the chronic illness is reflected by society, either through stereotypes and/or social context. Being involuntarily childless due to a chronic illness not only brings about disruptions to daily life due to the illness itself, but also the missing out on the day-to-day experience of life with a child. This is in addition to the two-fold effect of the significance of not meeting the norms of being healthy and having a suitable amount of children.

Bury (1982) describes the process of reacting and dealing with a change in the life course as biographical disruption. Biographical disruption is described by Bury (1982) as a way chronic illness can disrupt the basic understanding of the experience of everyday life and bring to the forefront issues of reciprocity and support within social networks. Chronic illness is often seen as a remote possibility, and is most often something that cannot be prepared for or planned. There are developmental stages of chronic illness (including infertility) that can be mapped onto biographical disruption. The first stage involves the disruption of taken for granted assumptions and behaviors about what life is and means. This first stage is when identity threats, such as changes to social status and interactions, begin to be recognized as part of the work ahead of the person (Mathieson & Stamm, 1995). The second stage brings about the disruption of the explanatory systems and requires a reassessment of one's biography and identity. Finally, the reevaluation of one's situation generates a response to the illness, which includes use of resources to respond to the illness. Similar to previous research on help-seeking behaviors for infertility, biographical disruption requires cues including symptoms, life course, individual and social cues, as well as enabling and predisposing cues to both recognize

and handle the biographical disruption taking place (Bury, 1982; White et al, 2006; Greil et al, 2011).

One of the concerns surrounding biographical disruption is the assumption that chronic illness happens in middle-age, which discounts conditions that appeared in childhood and have become part of one's accepted identity and biography (Williams, 2000; Wilson, 2007; Larsson & Grassman, 2012). Understanding the timing, context, and circumstances of illness and its contextualization in the life course as a problem or not can help to explain why an identity is threatened or not (Williams, 2000; Wilson, 2007; Larsson & Grassman, 2012). Even if childlessness is not considered a separate chronic condition, the acquired normalcy after a diagnosis is disrupted by the consequences of the infertility (Larsson & Grassman, 2012). Though some losses can be non-disruptive in the context of illness (i.e. leg amputation after the losing the ability to walk prior) (Larsson & Grassman, 2012), the loss of the ability to have a wanted child is disruptive, especially in a pronatalist society. When viewed as a consequence, rather than a separate illness, it is not unexpected as Bury (1982) described, but rather as a 'feared disruption to a hoped-for life course' (Larsson & Grassman, 2012).

### **Coping with Disruption**

Dealing with a biographical disruption can be complicated. Coping mechanisms can vary from patient to patient, even among those with identical conditions. Religion is often seen as a method of coping and healing and leads to better outcomes when the patient attributes control to God rather than other non-religious outside influences (Faircloth et al, 2004; Greil et al, 2010). Prior research has shown that God's will is one of the most important factors in recovering from an illness (Mansfield et al, 2002;

Faircloth et al, 2004). Whereas this applies in the case of illness, a different reaction manifests among women with infertility. Religion and associated activities often focus on the family, with most religious traditions encouraging childbirth which results in less acceptance of childlessness (Greil et al, 2010). The inability to have a child is often seen as a devastating failure, which leads to a higher commitment to get pregnant, especially among women (Ulrich & Weatherall, 2000; Parry, 2005; Greil et al, 2010). This commitment can be filled with uncertainty however, as religious beliefs can increase ethical concerns with ART (Singer, Corning, & Lamias, 1998; Greil et al, 2010; Shreffler et al. 2010). For women with a non-reproductive health barrier though, treatment is not an option and leaves three separate paths to resolve the disruption by only gaining a child to raise through surrogacy, adoption, or by remaining childless.

Adoption is often the next step considered by women with conventionally defined infertility for whom ART has not produced a pregnancy. Adoption compounds the feelings of failure when ART does not work (Jennings, 2010), but less so when ART is not an option. Surrogacy brings its own concerns among women with conventional infertility. Jennings (2010) found when interviewing women in treatment support groups the majority rejected surrogacy outright. Whether or not this might change when faced with the inability to utilize ART remains unclear.

Although previous research has examined infertility and chronic health conditions within the context of biographical disruption, none to my knowledge have looked at women with NHRBs specifically. Furthermore, to my knowledge none have been able to take advantage of a nationally representative random sample. Unlike many traditional qualitative studies that ask for volunteers based upon membership in a specific category, I

identified the women for inclusion in this study from questions asked of a nationally representative sample. An advantage to this approach is there is less concern about selection bias, however, there is less depth compared to traditional qualitative studies. This group is different from women with conventionally defined infertility because they are unable to have a child due to a non-reproductive health barrier, but are not necessarily infertile. The path, meaning, and response to their biographical disruption could differ in important ways from women with conventional infertility. Furthermore, the insights provided by women with NRHBs helps to better explain the process of problematizing and normalizing a primary health condition and the effects of the subsequent disruption of the inability to become pregnant. Moreover, the coping methods that women with NRHBs utilized by these women could guide interventions for women who are faced with the inability to pursue additional treatment or adoption for other circumstances.

Therefore, this study as described below, uses an exploratory method to find out how women define and experience having a non-reproductive health barrier to a wanted child through the lens of biographical disruption. This novel approach will expand the knowledge of both sociologists and medical professionals in the areas of fertility and health.

## **Methodology**

The National Survey of Fertility Barriers (NSFB) is a nationally representative survey of 4,794 women ages 25-45 with fertility barriers, including repeated miscarriage, sterilization regret and pre-existing health conditions (Johnson & White, 2009). Random digit dialing was used and interviews were completed between 2004 and 2007 through the use of Computer Assisted Telephone Interviewing (CATI). The response rate of 53%

to the screener question is typical of random digit dial surveys (McCarty et al, 2006), as was the final overall response rate of 37.2% (Johnson & White, 2009). The response rate is low compared to in-person surveys, yet it is fairly standard for telephone surveys (Keeter et al, 2006). In addition, the survey has been assessed for bias by comparing the NSFB to the demographic information in the Current Population Survey and the National Survey of Family Growth. The comparisons showed that even though the NSFB response rate was lower than the other surveys, the responses to the same variables were very similar to substantially more expensive surveys with higher response rates (Johnson & White, 2009).

The NSFB provides survey data based upon random-digit dialing, with over-samples from high minority census tracts, over-samples of women who meet criteria for infertility, plus includes women and their partners. The key criteria for inclusion as having a NRHB to a wanted child was answering yes to the question: “Did a physical problem ever keep you from having a baby you wanted?” In the NSFB, 423 women answered yes or maybe to the criterion question. In order to obtain the needed sample for the exploratory analysis, I excluded 391 women with a conventional infertility diagnosis. The current analysis therefore focused on the 32 women with a NRHB to a wanted child.

Most of the survey has questions with fixed choices responses. To capture additional comments or information, the interview protocol indicated that the interviewer should record comments and responses to questions without fixed categories in open-ended text boxes. At the time when the survey was administered, the research team did not emphasize recording unsolicited comments, therefore some interviewers may have been more conscientious than other interviewers in recording comments. Over half (n =

24) of the sample have open-ended responses, yet it is possible that all comments and responses were not captured. The open ended comments and responses ranged from a few words to a couple of sentences. Some respondents noted that the questions about pregnancy and child raising were particularly difficult due to their inability to have children. Additionally, the NSFB has a planned missing design to facilitate survey completion (Johnson & Young, 2011). The computer assisted telephone interviewing software algorithms randomly selected a subset of scale items for each of the 21 scales in the survey to shorten the overall length of the survey without sacrificing measurement of the key concepts.

In order to take full advantage of the data within the NSFB and still provide insights about a relatively “hidden” group, I used “survey-driven narrative construction” (Kazyak et al, 2014). Following the survey driven narrative construction approach, I translated both the open and closed survey responses by each of the women into narratives to be analyzed using qualitative coding. The survey questions responses were translated into a conversational tone in order to create the final narratives.

## **Findings**

### **<Insert Table 1 Demographics>**

#### *Defining Infertility*

As little research has focused on women with a non-reproductive health barrier to fertility, the demographic characteristics of those women with an identified non-reproductive health barrier and how they may or may not fit the criteria for infertility are important to understand. Table 1 outlines the descriptive statistics for the sample of women with a noted physical problem that prevented a wanted child. The sample

included 26 (81.3%) women who self-identified as White, three (9.4%) who self-identified as Black, two (6.2%) who self-identified as Hispanic, and one respondent who opted out of the survey prior to this question. The mean age was 37-years-old, with a range of 25 to 45 years of age. Married women make up nearly 63% of the sample, never-married women close to 31% and just over 6% are divorced. The average family income was nearly evenly split, with 14 (43.8%) of the women stating the family income was under \$40,000 per year, 16 (50.0%) stating the family income was over \$40,000 per year, and 2 (6.2%) refusing or not knowing the amount. The sample is more diverse in regards to education, with 31% of the women having a high school education or less, 47% with at least some college, and 19% with at least some graduate school. Thirteen (40.6%) of the women have given birth to at least one child, and 19 (59.4%) have not given birth.

**<Insert Table 2 Conditions>**

Table 2 details the non-reproductive health barriers (NRHBs) for each woman. For twenty-seven of the women, she had the NRHB, for four the partner had the problem, and for one couple both partners had NRHB. Twelve of the respondents did not give specifics of the nature of their NRHBs. Four of the women noted that one member of a couple had been sterilized to prevent a dangerous pregnancy due to NRHBs. The NRHBs varied among the group, ranging from concerns about medications, mental illness, paralysis, heart disease, and diseases of the nervous system. Additionally, concerns over arthritis, injuries, and surgical complications were mentioned.

The nature of the NRHBs do not automatically lead one to assume infertility. For example, heart disease and diseases of the nervous system are considered risk factors for

infertility, but they do not prevent pregnancy from taking place. Conversely, infertility does not automatically cue thoughts about the overall health of a women and their partners. This is exemplified by some of the regrets that the women expressed in their interviews. Heather, for example, wished she had more information in the beginning about her condition, which ultimately lead her to have a tubal ligation to prevent pregnancy. Hannah, who has had several open-heart surgeries, stated about her two children she had after her doctor warned her of the risks to her health “just I wish that people would realize what they're getting themselves into before they have a child and what the consequences are going to be”. Allison stated that after the premature birth and death of her son and after her doctor told her she would never carry to term “I wish I had more experienced doctors... more people that would listen to concerns first time mothers have”. Several of the women in the sample wished that a doctor or other health professional would have mentioned that their illness could have consequences for infertility. These statements exemplify the idea that even when the primary diagnosis is normalized as part of one’s life, the realization that there are implications for the ability to have a wanted child in combination with the lack of warning by medical professionals, can become a separate biographical disruption. As Stephanie, a young woman with physical health problems and depression stated, “Maybe I would have had kids earlier, if I had known”.

Many of the women do not fit the conventional definition of infertility: “a disease of the reproductive system defined by the failure to achieve a clinical pregnancy after 12 months or more of regular unprotected sexual intercourse” (CDC, 2016; WHO, 2016). Only five of the respondents stated that they had unprotected sex for more than 12



months without a pregnancy, either due to sterilization, a physical health condition which prevented ejaculation, or which ultimately resulted in a pregnancy after 2-4 years because, as Melissa noted, “we got lucky it just didn’t happen”. None stated they attempted to achieve pregnancy for more than 12 months without becoming pregnant (Table 2). Moreover, nearly half (15) do not identify as having problems with fertility or having trouble getting pregnant. Seven of the women stated that they might have problems getting pregnant but do not consider themselves as having a fertility issue.

### *Themes of Biographical Disruption*

As described in the literature review, Bury (1982) argues that biographical disruption consists of three stages. (1) the disruption of taken for granted assumptions and behaviors about what life is and means, (2) reassessment of one’s biography and identity, and (3) a response to the illness, including a use of resources to respond to the illness.

Below I summarize how many women with NRHBs fit stages of biographical disruption.

### *The Disruption and Threats to Identity*

There is evidence that many women with NRHBs experienced disruption of the taken for granted assumption that they will be able to have a wanted pregnancy. All of the women answered affirmatively that a NRHB prevented a wanted child. This alone is evidence that these women had a disruption of their taken for granted assumptions of what their life could have been.

Most of the participants described past experience with an NRHB, therefore many of the respondents have already passed through their most fertile years. When trying to understand how the respondents feel about having and/or raising children, however, there are questions that can help guide understanding of this sensitive issue. For example,

responses to the question: “Is it important to you to have kids?” indicated that most of the women (N=21) either strongly agreed or agreed (the remainder disagreed or strongly disagreed). Almost all of the women who had given birth by the time of the survey (12 of 13) selected the “very important or important” response. The divide between the women who had not already had children was evenly split at nine in each category.

I wanted to know, however, if the idea of having a child through the physical process of birth may have already been rejected by some of the women, and instead they might only desired to raise a child. This may have been a way of resolving the disruption, rather than ruminating over the loss of having a child. The NSFB asked the question “How important is it to raise kids?” Most of the women (N=24) selected the response indicating that raising kids was very important or important; few (N=8) disagreed or strongly disagreed. It was not surprising that all of the women who had children (N=13) indicated that it was important or very important to them to raise children; the women without children who also considered raising children important (N=11) provide evidence of biographical disruption from their NRHBs.

The women who did not have children, yet considered raising children important, are in a situation that suggests that their taken for granted assumption that they will be able to have children has been disrupted. Women and couples are often subjected to the ‘nuclear’ family structure in the media (Parry, 2005). These conceptualizations among women, however, tend to be fluid and adaptable to life experiences like infertility (Parry, 2005). As I discussed before, these women do not identify or qualify for infertility status, but are still unable to have the child they desire. Often, couples attempting to have a child but who are unable, will still tend to show a bias towards having biological children

rather than other alternatives. Much of this may be due to the social construction that womanhood and motherhood are viewed as essentially one in the same, creating the idea being childless is equivalent to failure (Ulrich & Weatherall, 2000). It may still be easier to either have hope to give birth to and raise a child of one's own or to reject the idea and begin to deal with the consequences. For example, Kimberly stated that she wanted to adopt, but "my husband does not share the same views as I do". Jenna's marriage failed because she wanted to adopt but "my husband didn't want to". Having a biological child overrode the desire to have a child to raise for the male partner in these couples.

In line with the idea of a having a biological child whenever one is desired, the social expectations in a pronatalist society has the added identity threats of stigma and social role change. The NSFB asked the women three questions relating to the perceived stigma of being unable to get pregnant and infertility. Only 22 women were asked 'Do people who have difficulty getting pregnant find it embarrassing?' About half (N=14) indicated that it is embarrassing. Of the 20 women who were asked: 'Do people who cannot get pregnant without medical help feel inadequate?' more than half indicated that they do (N=15). One more question was asked to determine perceptions of the stigma of infertility, 'People who experience infertility often feel that family and friends look down on them?' Less than half (N=10) of the 22 women indicated yes. There is an indication that at least some of the women with NRHB perceive infertility as stigmatizing, and therefore is a threat to their identity.

There were five question in the NSFB relating to the women's perceptions of social roles of as women with no children. The women were asked if they agreed with the statement 'Holidays especially difficult for me because I do not have kids' of which one

of the nine women agreed with the statement. The second statement 'Family get-togethers are especially difficult because of not having kids', to which one out of nine women asked agreed with. The next, 'I can't help comparing myself with friends that have kids' was agreed to by six of the fourteen women asked. Of the ten women asked, half agreed with the statement that 'When I see families with kids I often feel left out'. Finally, three of the fourteen women asked agreed with the statement 'When people I know are pregnant I often feel sad'. Several observations were made here. It seems that social role perceptions when they involve family and friends are less often agreed with than those that are asked in a more general nature. This may be indicative of the knowledge those close relationships have of the non-reproductive health barriers. The higher level of agreement to the statement regarding feeling left out around families with children is also telling as the women are showing the disruption of having an unplanned life course change.

#### *Reassessment of Biography and Identity*

Many of the women sought advice or encouragement from their spouses and their families/friends as a way to begin to renegotiate their identity. Of the twenty married women, eighteen were asked if their partners encouraged them to seek medical help. The responses were mixed among the women, with five stating they did not know or remember, one refusing to answer, seven stating their spouse was encouraged seeking medical help, four stating they got mixed support for and against seeking medical help, and one stating that her spouse discouraged seeking help. For these women, the response of their family and friends were the same as their spouse. The exception to this is Kassie, whose husband discouraged her from seeking help because they already had children at

home and she has surgical complications as well as diabetes. Kassie did not discuss her concerns with her family and friends, despite reporting that she has very good social support. None of the women had meaningful contact with women in a similar situation as themselves. As Allison stated in her interview, 'I didn't know anyone who had the same problem as me'. Unlike conventional infertility where a support group may be just a click away on the internet, access to a group with the specific concerns of these couples may be harder to find.

Eight of the women who were unmarried at the time of the interview responded to the question regarding talking to family and friends about seeking medical help to get pregnant. Of these women, two reported that they talked to family and friends often, and six stated that they rarely or never talked about seeking medical help to get pregnant. Although the majority of the women who did talk to their family and friends found encouragement, Sky did not. Sky has had two previous abortions, and two children without a partner and has an unspecified non-reproductive health barrier to pregnancy. Sky reports that she has very little social support, and it is difficult to say if her health or reproductive history has affected the support for her to seek medical help to become pregnant.

In these cases, however, many of the women could not pursue medical intervention due to their or their partner's NRHBs. This leaves few options to become a parent. Adoption is one such option, but it can be interesting as it can either be rejected in favor of hoping for a biological child, or accepted as a way to bring infertility to a resolution. Six of the eight women who stated raising children was somewhat or not important stated they had considered adoption. Raelynn, who cannot have a child due to

her NRHB, states that she considered adoption but rejected the idea because she did not want to be a single mother, which meant the timing wasn't right. Luann considered adoption as it was the best thing due to her NSRB, but decided against it due to financial reasons and the amount of care her husband requires for his disability. Carla and her husband discussed it because of their combine NRHBs, but never seriously because it was not financially feasible. Kimberlee wanted to adopt to share her home with a child who didn't have hope, but her husband did not share her feelings so she was unable to adopt. Jenna wanted to adopt and wasn't able to because her marriage failed, and now she doesn't want to adopt at all. Stephanie wanted to adopt and couldn't because of her health issues. All of these examples add to the possibility that not finding having or raising children as important is the result of the reassessment of the women's identity and biography, rather than a statement of their original life plan.

Given the rejection of adoption on various grounds, the final possibility of having a wanted child is through surrogacy. Twenty-five of the women were asked if they had ethical issues with surrogacy or gestational surrogacy. For surrogacy, 16 of the 25 stated they had at least some ethical concerns, and 12 of the 25 stated they had at least some ethical concerns with gestational surrogacy. Surrogacy, however, is more expensive than adoption. This may mean that the women who are amenable to surrogacy find it cost prohibitive as well.

Many of the women have or are in the process of reassessing their biography and identity. Hannah, a 40-year-old married woman, is an exemplar of a woman who has been through the process of reassessing her biography and identity. Hannah was advised by her physicians not become pregnant due to her heart disease. Hannah, had two

children after birth control failures, however, against the advice of her doctor. Prior to and as a result of , she had three open heart surgeries before her first child and one after, as well as two strokes during her first pregnancy. Following her second pregnancy and her doctor's firm insistence that she no longer has children, her husband had a vasectomy. Hannah still wishes "that I was rich enough to give my husband his ball team" (it was a running joke that husband wanted enough kids for a ball team), yet, she has accepted that this is her new life. Hannah stated that "I wish that people would realize what they're getting themselves into before they have a child and what the consequences are going to be" which allows us to see that she had been grappling with the dual diagnosis of not only having a serious, life threatening diagnosis and the enforced end of her child-bearing years at the time of her birth control failures.

#### *The Response to the Disruption*

There is no more permanent way to respond to feeling as though pregnancy may be dangerous or being directed to not get pregnant, than sterilization. Four of the women in this sample decided to pursue sterilization as a final end to their reproductive years. Raelynn and Michelle both had tubal ligation to prevent pregnancy due to their NRHBs. The husbands of Hannah and Phillis had vasectomies to prevent pregnancy due to their wives' NRHBs. The permanency of this solution does not seem to have had an effect on the relationship these four women have with their partners, in fact, the relationship satisfaction may be a sign that the couples were working through the disruption together. They all state they are happy with their relationships and their sex lives, and have not had discussions about ending their relationships. Additionally, despite the fact that each woman and her partner place varying importance on having and raising children, each of

the women report high life satisfaction, and only Raelynn feels that she might do things differently if she had a chance at a do-over.

Raelynn is an exemplar of the process of responding to a disruption. Although her life may seem ideal even after her response of sterilization to her inability to have children safely, she still reports that not being able to have children leaves her feeling a bit cheated by life. She reports, however, that not being able to have children has opened up new opportunities for her and she actually feels relieved that she now cannot physically have a child.

Religion is another well researched way of dealing with the disruption of illness. Less is known about its functioning when combined with the realities of being unable to have a wanted child due to the illness. Religion is often seen as a way to cope with an illness, but can lead to less acceptance of childlessness in those who are infertile (Faircloth et al, 2004, Greil et al, 2010). The idea that religion could be both a source of healing and a source of grief is interesting in a group where they must deal with both an illness and the resulting inability to have a child.

The women were asked how often they attended religious services. Twenty out of the twenty-one women asked attended at least once a year or more, and eight stated they attended services at least one time a week. Of the twenty-three women who were asked if they prayed, twenty-one stated they prayed at least once a day, if not several times a day. Thirty of the women were asked if they felt close to God, and twenty-nine stated they felt somewhat or very close to God. Twenty-two of the twenty-three women asked stated that their relationship with God affected their daily lives at least a little. Overall, the group as a whole showed a high level of religiosity. This is evidence of the connection between



coping with illness and religion. Of the women, 17 felt that if it was God's will they would achieve, or had previously achieved, pregnancy.

Rebecca is an exemplar of this group. She reports that she is Protestant, prays at least once a day and feels somewhat close to God, which influences her life quite a bit. She reports that her health is fair and that she is paralyzed. Although she is not currently trying to have a child her husband and her have decided to let God's will, rather than medical intervention, decide if she will become pregnant. Rebecca does not report a sense of urgency about becoming pregnant. Rebecca feels that her life is close to ideal and that she is satisfied with it, however, she is missing some important things in life.

Three of the women were specific that God would have nothing to do with them achieving pregnancy. Dominique is an exemplar of this group. Dominique reports that she is a Christian who prays at least once a day and feels somewhat close to God, and this somewhat influences her day to day life. Dominique states she is in fair health, and has arthritis as well as kidney/liver/bowel problems. She feels strongly that she will only be able to achieve pregnancy with medical intervention, and that God will have very little to do with her succeeding. She feels a sense of urgency about getting pregnant. Dominique shows low life satisfaction and does not feel like she has gotten the things important to her in life.

Whereas Rebecca and Dominique seem similar on the surface, they have two very difference responses to their inability to have a child. Rebecca seems to have used religion as a method of coping (God's will), however, Dominique seems to be very much still in the process of reassessing her identity and biography and exhibits some of the same behaviors (e.g., unacceptance) as women with traditional infertility. It is hard to say

based on the information found in their survey responses, but this may be due to Rebecca being more focused on her health condition and Dominique being focused more on the infertility. Additionally, none of the women report being angry at God regarding any part of their situation.

## **Discussion**

The exploratory survey-driven narrative analysis of women with a non-reproductive health barrier to a wanted child allows for a glimpse into experiences of couples with NHRBS. There are, however, some important limitations to note here. First, the sample size is small and due to the nature of the planned-missing design of the NSFBS, not all of the questions were asked of the entire sample. This is offset somewhat by the random sampling, allowing for the ability to group these women after the fact and avoid self-selection bias. Furthermore, many of the open-ended responses were limited due to the women not identifying as infertile. It is possible that interviewers found the women who thought of themselves as having a problem as being more interesting, and therefore could have written down more comments from the women. Future research would benefit from recording interviews and consistent emphasis with interviewers to write down participant comments. It is important to keep these limitations in mind while interpreting the results of the study, however the data nevertheless presents a unique glimpse into this understudied population.

Women and couples with a non-reproductive health barrier to a wanted child may better be reflected in the social construction of childlessness used prior to the medicalization of infertility. Many of the women wanted to have a child, and for those who are unable to have children raising children is still high in importance. Unlike

women who are conventionally infertile and desire a child, women with non-reproductive health barriers have limited options to have and/or raise a child. As survey-driven narratives have shown, adoption is often not an option due to conflicted feelings of the couple or financial concerns due to the health condition of one or both of the partners. The possibility of using a surrogate has a twofold effect of being both cost prohibitive and ethically concerning. In addition, they do not identify themselves as infertile and their health conditions are varied, so support from conventional infertility support groups are not necessarily a helpful source of support. Moreover, discussion of the consequences of a diagnosed health condition on fertility is important to women with NRHBs. The consequences of the lack of discussion has been studied extensively in patients with cancer, but having these types of conversations with couples who face NRHBs is needed.

Biographical disruption and its processes are evident in the survey narratives. I looked at themes that described, (1) the disruption and threats to identity, (2) the reassessment of biography and identity, and (3) the response to the disruption. I found evidence of biographical disruption and identity threats in the survey responses. For example, women who wanted to raise a child found barriers in the form of a spouse who did not want to raise a non-biological child. Additionally, women felt that they were stigmatized for being unable to have a child and felt left out from peers with kids and families. These social stigmas and feelings of missing out on the social role of parenthood required the women to reassess who they were as a woman.

In order to begin to reassessing their identity, women who were unable to have a wanted child began to exploring their options. Many spoke with their partners as well as their friends and family about pursuing medical treatment, and found encouragement

from these sources. Although it is unclear what medical options and confirmations of their conditions they may have pursued, there is evidence that this was the beginning of the reassessment of their identities. There was also the pursuit and consideration of adoption, which due to circumstances such as financial feasibility and health limitations was rejected by the couples. Even though surrogacy could be a second option, findings show that some of the women feel surrogacy is unethical. In addition, surrogacy is more expensive than adoption and would be even more cost prohibitive to couples facing medical bills as well.

The loss of being able to bear a wanted child and having no options left to pursue a child meant that these women needed to be able to formulate a response to their disruption to fully move forward. After experiencing the disruption and reassessing their biography and identity, the couples with NRHBs began to make final decisions regarding their fertility. Sterilization as a permanent end to childbearing was chosen by a few women. Though this left them open to feeling cheated by life, it also opened them up to the ability to pursue other opportunities and brought a sense of relief with its finality. I found that even within this group, and overall, the women stated that their relationships and sex lives were happy. This is a sign that the couples were working through the disruption together. In addition, I found that religion is often used as a coping method for these women, dependent on where they were at in their disruption.

The couples with NRHBs exposed a new idea that is worthy of exploration. One of the powers that women without a NRHB have over couples with NRHBs is the power of choice. Women who have conventional infertility have the option to pursue a medical treatment with which they can have a wanted biological child, they may have more

financial means free to adopt a child, or forgo having children altogether and remain child-free. Women with NRHBs in this dataset show that these choices may not be an option when facing a serious medical condition. The couples facing NRHBs may be more similar to the infertile women prior to the options provided by the advent of ART. Additionally, unlike women with cancer who may be able to preserve fertility via medical procedures, women with NRHBs are not facing infertility in a clinical sense. Moreover, these effects are seen not only in the cases of those without children, but in the women who faced the loss of a wanted child after having children previously. For men and women facing the non-choice choice of not having children, the inability to have a wanted child becomes part of the sick role, and the chronic illness or injury which is preventing pregnancy becomes the master medicalization status. Further research using traditional qualitative methods, such as interviews, are needed in order to understand this population further.

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**Table 1. Descriptive Statistics National Survey of Fertility Barriers, Women Unable to have Children due to Non-Reproductive Health Barrier (N = 32)**

<b>Age in years</b>		
25-30	5	15.6
31-35	6	18.8
36-40	10	31.2
41 and older	11	34.4
<b>Race/ethnicity</b>		
White	26	81.3
Black	3	9.4
Hispanic	2	6.2
Refused	1	3.1
<b>Marital Status</b>		
Married	20	62.5
Divorced	2	6.2
Never married	10	31.3
<b>Family income</b>		
Less than \$40,000	14	43.8
More than \$40,000	16	50.0
Don't know/refused	2	6.2
<b>Years of education</b>		
High school or less	10	31.2
Some college	9	28.1
College graduate	6	18.8
Graduate school or more	6	18.8
Don't know/refused	1	3.1
<b>Ever given birth</b>		
Yes	13	40.6
No	19	59.4

**Table 2. Physical Health Barriers to a Wanted Pregnancy (N = 32)**

Name	Age	Marital Status	# of Children	>12 Mo. Attempted Pregnancy or Unprotected Sex w/ No Pregnancy	Non-Reproductive Health Barrier	Affected Person
Kassie	41	Married	1	No/No	Surgical Complications	Respondent
Dominique	32	Never Married	0	No/No	Arthritis/Kidney/Bowl/Liver	Respondent
Taylor	41	Never Married	0	No/No	Non-Specified Non-Reproductive Health Barrier	Respondent
Carol	38	Married	2	No/Yes	Arthritis	Respondent
Jessica	28	Never Married	0	No/No	Kidneys/Stomach	Respondent
Lisa	27	Never Married	0	No/No	Paralysis	Partner
Raelynn	38	Never Married	0	Never Tried/No Unprotected Sex	Non-Specified Non-Reproductive Health Barrier with Sterilization	Respondent
Laura	34	Married	1	No/No	Non-Specified Non-Reproductive Health Barrier /Chronic Health Condition	Respondent
Channing	37	Never Married	0	No/No	Arthritis	Respondent
Michelle	45	Married	2	No/Yes	Subarachnoid Brain Tumor/Cyst with Sterilization	Respondent
Marlene	48	Married	2	No/No	Non-Specified Non-Reproductive Health Barrier	Respondent
Marla	36	Divorced	2	No/No	Non-Specified Non-Reproductive Health Barrier	Respondent
Phillis	42	Married	0	No/No	Non-Specified Non-Reproductive Health Barrier with Sterilization	Respondent
Hannah	40	Married	2	No/Yes	Open Heart Surgery/Valve Replacement with Sterilization	Respondent
Verna	35	Married	0	No/No	Non-Specified Non-Reproductive Health Barrier	Respondent
Sky	39	Divorced	2	No/Yes	Non-Specified Non-Reproductive Health Barrier	Respondent
Luann	43	Married	0	No/No	Hydrocephalus	Partner
Annmarie	41	Married	0	No/No	Non-Specified Non-Reproductive Health Barrier	Respondent
Carla	26	Married	0	No/No	Back Injury/Surgical Complications/Unable to Ejaculate/Automotive Accident	Respondent and Partner
Clarinda	39	Married	0	No/No	Non-Specified Non-Reproductive Health Barrier	Respondent

Heather	45	Never Married	0	No/No	Steroid Medication	Respondent
Kimberlee	44	Married	0	No/No	Non-Specified Non-Reproductive Health Barrier /Menopause	Respondent
Lily	32	Married	2	No/No	Work-related Injury	Partner
Kenzie	44	Married	2	No/No	Non-Specified Non-Reproductive Health Barrier /Chronic Health Conditions	Respondent
Zoe	30	Never Married	0	No/No	Chronic Migraines/Stroke Risk/Medication Issues	Respondent
Jenelle	39	Never Married	1	No/No	Mental Illness/Substance Abuse/ Non-Specified Non-Reproductive Health Barrier	Respondent
Melissa	32	Married	1	No/Yes	Fibromyalgia	Respondent
Davena	25	Never Married	0	Never Tried/Never Tried	Surgical Complications	Respondent
Allison	33	Married	1	No/No	Prescribed due to Pregnancy Complications	Respondent
Jenna	41	Married	0	No/No	Surgical Complications	Ex-Partner
Rebecca	41	Married	0	No/No	Paralysis	Respondent
Stephanie	40	Married	0	No/No	Mental Illness	Respondent