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Medical conditions, pregnancy perspectives, and contraceptive decision-making among young people: An exploratory, qualitative analysis

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Abstract

Objective: To explore perspectives on family planning among young people who perceive they are infertile or will have difficulty carrying a pregnancy to term owing to medical conditions or procedures.

Methods: This exploratory analysis examined pregnancy plans and contraceptive behavior among 12 young adults with a diagnosed medical condition or who had undergone a medical procedure associated with impaired fertility, and who had discussed fertility with a healthcare provider. We utilized data from a larger study investigating prospective pregnancy intentions and plans among 50 young (ages 18-24) women and their male partners (n=100).

Results: Medical conditions included endometriosis, polycystic ovary syndrome, and lupus. For some, medical conditions/procedures led to use of no or less effective contraception, as perceived risk for pregnancy was low, though seven participants had previously experienced pregnancies. Participants also described how medical conditions altered their timelines for pregnancy and overall desire for children; for example, one participant described continuing an unplanned pregnancy because she feared it would be her only chance to parent.

Conclusion: This exploratory analysis suggests that among young people, medical issues perceived to affect fertility and pregnancy may influence pregnancy planning and contraceptive behavior. Young people may lack knowledge about fertility and the impact of a medical condition; thus it is critical that providers clarify the difference between anticipated difficulty conceiving and complete infertility. Tailored contraceptive care is needed for young adults with medical conditions that may affect fertility to ensure they have the necessary information to make informed family planning decisions.

Implications

Medical conditions known to affect fertility may influence young people's family planning desires and behaviors. Understanding how young adults process information about medical conditions' impact on their fertility and change or make plans in response is important in order to best meet their family planning needs.

Keywords: perceived infertility; PCOS; endometriosis; pregnancy; family planning; emerging adulthood

1. Introduction

Many women in the United States have medical conditions that may affect their ability to become pregnant; for example, while estimates vary depending on diagnostic approach, methodology, and population [1-4], between 2% [5] and 7% [6,7] of American women may have polycystic ovary syndrome (PCOS), while approximately 11% [8] may have endometriosis. Although these conditions are typically diagnosed in reproductive-aged adult women, PCOS, endometriosis, and other reproductive conditions may emerge in childhood or early adolescence [9,10]. While the reproductive sequelae of these conditions are not fully understood or uniform across patients, they frequently include compromised fertility [1,11-14]. Additionally, conditions such as lupus, PCOS, and endometriosis may be associated with pregnancy-related complications, including miscarriage, preeclampsia, and preterm birth [15-17].

Furthermore, many young people believe they will have difficulty getting pregnant [18-27]. A 2018 study found that 17% of young women felt that it was unlikely they would experience a future pregnancy [18], while in a 2012 study of unmarried young adults, 19% of women and 13% of men believed they were likely to be infertile [19]. Contrasting these data with national estimates suggests a tendency to overestimate infertility; for example, the National Center for Health Statistics estimated that approximately 7% of married or cohabiting women aged 15-44 are unable to become pregnant, and that 12% of all women aged 15-44 have difficulty getting pregnant or carrying a pregnancy to term [28]. Research suggests a variety of reasons why an individual may anticipate difficulties with pregnancy [19,20]. For example, some people overestimate their infertility if they do not become pregnant after what they consider to be a prolonged period of unprotected sex; in one study, 37% of women who believed they were infertile cited absence of pregnancy after sex without contraception as a reason for their belief [19]. This is particularly relevant in the context of common messaging to adolescents that

pregnancy can happen after only one sexual encounter [29]. One qualitative study of adolescent girls found that many had misperceptions about what causes infertility, including stress, substance abuse, and contraception, which could lead some to incorrectly perceive themselves as being infertile [30]. Additionally, some women may anticipate difficulties becoming pregnant if family members have experienced fertility difficulties, including miscarriage [20]. Conversations with a healthcare provider, such as a provider stating a low likelihood of becoming pregnant owing to a medical condition or undergoing procedures known to impact pregnancy, may also lead people to (possibly incorrectly) believe that they are completely infertile [20].

The extant literature suggests that because the medical community lacks knowledge about the origins, symptoms, treatments, and disease progression of conditions such as PCOS and endometriosis, patients may also lack clarity on treatments and prognosis, especially relating to fertility [31-37]. Indeed, in one qualitative study, women affected by endometriosis described becoming their own experts, educating themselves about their conditions when their providers were unable to do so [35]. Furthermore, some clinicians may neglect discussing fertility with their patients [37], not take conditions seriously [35], and dismiss patients' complaints about pain, often leading to delayed diagnosis [38-40]. This is especially important for Black women, who experience the highest rates of infertility [41], who may have differential rates and experiences of medical conditions that can affect fertility [6,42-44], and for whom the U.S.'s history of reproductive oppression, including forced sterilization, may make less likely to interact with and/or be distrustful of the medical system [45-48].

Previous research suggests that young people who perceive their fertility is compromised are less likely to use contraception [19,21,22,26,49-51]. Research among women and adolescents in the U.S. has found that perceived infertility was commonly cited as a reason for contraceptive

non-use prior to pregnancy [20,23,24,27,49]. While several quantitative studies have examined contraceptive use for pregnancy prevention among women with medical conditions associated with impaired fertility [52-55], to our knowledge, only one qualitative study has addressed these issues among young people (specifically adolescents) [56]. To fill this gap, we analyzed in-depth interview data to explore the influence of medical conditions on young adults' pregnancy desires and plans, and contraceptive behavior.

2. Methods

This analysis utilized data from the Young Couples Study, a mixed methods study examining pregnancy desires and decision-making among 50 couples (total n=100) in Northern California. The aim of this study was to develop new approaches to prospective measurement of pregnancy intentions. Eligibility criteria included that the female partner: self-identified as Latina or Hispanic, Black or African American, Asian, or White; was between ages 18 and 24; was not currently pregnant or trying to become pregnant; and could identify a primary male partner age 18 or older with whom she was sexually active and had been in a relationship with for at least two months. Both partners had to live in Northern California. We utilized a theoretical sampling approach, iteratively shifting our focus to different populations in order to yield a sample with maximum diversity in racial/ethnic background, educational attainment, and parenting status [57]. We recruited participants through flyers posted by community organizations, health clinics, and colleges, and through the online advertisement website Craigslist and Facebook.

After participants provided informed consent, they first completed a brief survey on demographic characteristics and several pregnancy-related measures. The survey included the following question: "Some people are unable to become pregnant, even if they want to. How

likely do you think it is that you are infertile or will have difficulty getting pregnant when you want to?” with the response options “not at all likely,” “slightly likely,” “quite likely,” and “extremely likely.” [58]. Interviewers of the same gender as the participant then conducted individual interviews simultaneously and separately using a semi-structured interview guide that addressed relationship history, contraceptive decision-making, and pregnancy intentions. Interviewers also probed on responses to the survey items on pregnancy-related measures, including the question on perceived likelihood of infertility. Upon interview completion, each participant received an incentive of \$30. The Committee for the Protection of Human Subjects at the University of California, Berkeley approved the study protocol.

Interviews were recorded digitally and professionally transcribed. This exploratory analysis included 12 participants who described medical conditions that may affect fertility or are associated with pregnancy-related complications, as well as previous medical procedures that may affect fertility (e.g., intensive radiology treatments, complications with a prior intrauterine device). This information emerged spontaneously or through probing about responses to the survey question about difficulty becoming pregnant. This analysis focused on the subpopulation of participants who had believed themselves to be infertile owing to medical conditions or procedures *and* discussed the potential impacts of their conditions on their fertility with a healthcare provider. We conceptualized this group a distinct from young people who perceive themselves to be infertile for other reasons, including misperceptions about their fertility [19,20,22,25].

Two authors (SA and NI) coded the data in the web-based software Dedoose in two rounds using a thematic analytic approach modified to incorporate collaborative coding to enhance analysis [59,60]. First, we utilized a “lumping” approach, analyzing and coding larger

blocks of text to capture the larger topics and ideas, followed by a second round of coding using a final code list developed by condensing similar codes to capture emergent themes [59]. We present a variety of data—participant demographics, descriptive results of the perceived infertility survey question, themes developed through analysis of the qualitative interview data, and a case study vignette—in the interest of providing “thick description” [61] to triangulate an initial conceptualization of the influence of medical conditions on family planning among young people. We first describe the demographic characteristics of the participants in our sample with perceived infertility due to a medical condition or previous medical procedures. We then present qualitative data, using pseudonyms, to illustrate the influence of perceived infertility on contraceptive decision-making and pregnancy plans and desires.

3. Results

In the subsample (n=12), 11 participants perceived infertility owing to a medical condition or complications from a previous medical procedure, including PCOS, endometriosis, and ovarian cysts, while the twelfth expected difficulties carrying a pregnancy to term owing to lupus (Table). Among this subsample, the average age was 21.5 years (SD=1.7). Most participants were women (n=10) and had been in a relationship for longer than a year (n=10). Over half (n=7) reported prior pregnancies (with all but one pregnancy considered unplanned), and five were parents. Notably, the majority of participants (n=7) were people of color.

Responses to a question about perceived infertility on the demographic survey varied. When asked how likely it would be that they would have difficulty getting pregnant or getting a partner pregnant, one participant responded that it was extremely likely, two selected quite likely, six selected slightly likely, and three selected not at all likely (Table). We observed a

pattern in these responses, in that participants who had previously experienced pregnancy appeared to not anticipate difficulties becoming pregnant, while those who had tried intentionally to become pregnant and had not been successful expected some degree of difficulty. For example, three female participants who felt that it was not likely they would experience difficulty had all been pregnant before. Cassie, a woman with ovarian cysts and one previous pregnancy, described, “It’s like, you know, I think I can get pregnant...I mean I already have once, so I don’t see myself having difficulties in the future.” In contrast, two participants who had tried to get pregnant for at least a year and had not conceived reported that it was extremely and quite likely they would have difficulty getting pregnant, while most who reported that it was slightly likely had never tried for a pregnancy before. All 12 participants described medical conditions or previous medical procedures as influencing their thoughts and behaviors regarding pregnancy and/or contraception, as described below and in Holly’s vignette (Figure).

3.1 Influences on contraceptive decision-making

In the qualitative interviews, some participants described how perceived infertility led to use of no or less effective contraception. Like Holly, these participants felt that, because of their medical conditions or previous medical procedures, they would be unable to become pregnant, rendering contraceptive use unnecessary. For example, Jake, a man who had undergone intensive radiology treatments and had no previous pregnancies, described his decision to stop using condoms.

“Because of all the x-rays at such a young age, they said it was highly possible that I might not be able to have kids. That I might be sterile. So that I feel like subconsciously

that might also play into why I stopped wearing condoms, was because I kind of rationalized it to myself.”

Jake was in a committed relationship with someone he planned to have children with in the future. Despite the shared, clear desire to avoid pregnancy they both described, his perceived infertility was the reason he stopped using condoms and started relying on withdrawal, a method he acknowledged as being less effective. When describing how he came to this choice, he stated, “I was like, okay, well if I’m pulling out, and I’m not even sure if I can have kids...I think that factor, in the back of my mind, kind of has an effect on my decision-making.” Simone, a woman with endometriosis and one previous pregnancy, also recalled her experience discontinuing contraceptive use after her healthcare providers told her that, because of her medical condition, “You’re just never having a kid.” Because she perceived a minimal chance of pregnancy, she decided contraception was not necessary: “I’m just gonna be loose and wild, and I don’t give a shit. And so [partner] and I just never used protection because of that.” Simone went on to experience an unplanned pregnancy with her partner. While she did not want to be pregnant at the time, she had a positive emotional response to the pregnancy, owing to her perceived infertility and family troubles she was experiencing at the time. “I was really happy I was pregnant, though, because my doctors told me I’d never have kids. And then obviously when I found out I was going to have a kid, I was in shock, but I was so happy, I didn’t care.” She saw the pregnancy not only as a chance at motherhood that she had thought she might never have but also as the “family that I wanted, or needed, in a sense.” Similarly, Karina, a woman who previously had thyroid cancer and been pregnant once, described how she and her partner decided to have sex without using contraception: “Well honestly, that’s what we’ve been doing the whole time. And I don’t get my period because I had thyroid cancer when I was 18, and they

had to remove my thyroid, and I take medication every day. And I'm kind of ruined, like I don't have the monthly cycle anymore. And that's what happened with [daughter], like I thought I can't get pregnant, surprisingly I did." Even though Karina was avoiding pregnancy at the time of her interview, she described that she would be both happy and unhappy if she were to find out that she was pregnant today. "I want to finish school first, but at the same time, I have two answers for that, a little unhappy and happy just because I feel like I can't get pregnant, and it's more out of luck for me. More luck for me, I guess, than actual planning..."

For four participants, medical conditions influenced contraceptive method choice, rather than overall use or non-use. These participants considered methods that would help alleviate their ovarian cysts, not exacerbate their uterine scarring, or would not interfere with their medication.

3.2 Influences on pregnancy plans, desires, and feelings

Like Holly (Figure), whose PCOS diagnosis led her to feel both nervous and excited about an unplanned pregnancy, other participants also described how their medical conditions or previous medical procedures influenced their reactions to unplanned pregnancies. Jessica, a woman with ovarian cysts and a previous pregnancy, recalled how, at age 16, she "had a breakdown" when she found out she was pregnant. Ultimately, she and her partner decided to continue the pregnancy, owing to fear of infertility. "We talked about that, what if I can never get pregnant again? What if this is my only chance of having a kid? So I think yeah, that did play a factor in figuring [it] out." Even though Jessica was not sure if she would try to become pregnant again, her perceived infertility was still a factor in her decision-making; when asked if her ovarian cysts influenced how she thought about pregnancy or contraception, she said, "It does, of

course. Especially because in the back of my mind I'm like, what if this is my last pregnancy? What if I never get pregnant again?"

Additionally, some participants described how medical conditions or previous medical procedures influenced their timelines for having children. Denise, who had been pregnant once, described openness in her pregnancy timeline because of her Lupus diagnosis: "Yeah, so if I'm like 26, and they're like, yeah, you're in remission, and I'm in a good place with everything else, I figure that might be the time. So I wouldn't want to wait necessarily in case I get sick again." Although Denise would prefer to wait until age 27 or 28 to become pregnant, she also recognized the need for flexibility in those plans because she could not predict the status of her lupus. After being told by her physician that she would need to proactively take medication to prevent miscarriage if she were not in remission, and experiencing a previous unplanned pregnancy and subsequent miscarriage during a Lupus flare-up, she realized that becoming pregnant would not be an issue; rather, carrying a pregnancy to term would pose a challenge. Because of this, she said, "Family planning for me would probably go around when I'm in remission."

Finally, two participants described how their perceived infertility affected their overall desire for children. The ways these participants expressed their pregnancy desires were colored by the difficulties they expected to face getting pregnant, carrying to term, and delivering a healthy infant. Sandra, a woman with endometriosis and no previous pregnancies, noted that she did not want to have children until she found out she couldn't become pregnant: "That's always how they say it is, you never want something until you know you can't have it." She described a history of unprotected sex with her current and previous partners, hoping that one of them would be the one to bring about a "miracle" and get her pregnant. While she strongly desired a pregnancy with her current partner, she noted that becoming pregnant would be "a blessing and a

curse”; knowing she could get pregnant would bring her much joy, but she did not feel financially ready to parent a child. While Sandra’s perceived infertility influenced her desire to have children, Alisha, a young woman with PCOS and no previous pregnancies, felt conflicted in her desire to have children owing to her perception of infertility and potential difficulty in sustaining a pregnancy. After being told by her physician, “your situation limits you a lot,” she described the lack of control she felt she had over getting pregnant: “It all has to do with my condition pretty much. It’s like I said, it’s not up to me really.” Although she strongly wanted to become pregnant, this participant had suffered disappointment and frustration after a year of trying to become pregnant without conceiving. This disappointment was amplified by her partner’s strong desire to have a child and her feelings about what her PCOS diagnosis might mean for their relationship: “I always tell him, like you’re probably going to leave me for someone who can bear children.” The seemingly conflicting desires exhibited could lead her to appear ambivalent about pregnancy; instead, her interview later revealed an internal negotiation process that served as a form of self-protection against the potential disappointment and pain of being unable to actualize her childbearing desires (further described elsewhere [62]).

You want to have a child as opposed to the fact that you know that your body can’t even really so much as take a child. Then it’s like, do I even want one? Do I? Like do I want to put myself in that situation where I might possibly lose my baby? I feel boxed in.”

Because of this, she described herself as being “50-50,” both not actively trying to get pregnant and not actively avoiding pregnancy. Like many others in this sample, her medical condition and resultant risk for infertility tempered her true feelings and behaviors around childbearing.

4. Discussion

This exploratory analysis suggests that among young people, medical conditions and procedures perceived to affect fertility and pregnancy outcomes may influence approaches to pregnancy planning and contraceptive behavior. Importantly, this exploratory analysis illustrates a complex dimension of reproductive decision-making among young people that merits consideration in family planning care and should be further explored in both quantitative and qualitative research.

While previous research has examined young people's perceived infertility owing to the absence of pregnancy after unprotected sex [19,24,27,49], our study expands the literature by focusing on individuals whose perceptions are related to their health status and conversations with healthcare providers. Young people may generally lack accurate information about fertility; for example, 92% of unmarried young adults overestimate the probability of pregnancy after one act of sex without contraception [19]. They may also have inadequate knowledge of their own medical conditions and health status [63]. There is likely an interaction between this normative lack of knowledge about fertility and knowledge about how a medical condition can affect their ability to conceive and/or carry a pregnancy to term. As young people affected by medical conditions likely have more intense relationships with the healthcare system, prioritizing sex education and discussing fertility in a developmentally appropriate manner during healthcare visits is critical for supporting their informed decision-making about pregnancy and contraception. Given that more than half of this subsample had experienced unplanned pregnancies—which granted, many were quite pleased about because they expected pregnancy would be difficult or impossible for them—this analysis suggests that young people with these conditions may be making decisions about contraception without full and accurate information. It is critical that providers delivering this information make clear the difference between

anticipated difficulty becoming pregnant and complete infertility, as well as communicate the degree to which the scientific evidence is not conclusive. However, in order to do so, providers themselves must be knowledgeable of medical conditions that may impact an individual's fertility, including endometriosis and PCOS. Notably, our subsample was also primarily comprised of women of color, drawn from a larger study with a diverse sample by design [64]. In general, the *overrepresentation* of women of color among people affected by infertility [41] but *underrepresentation* among people receiving healthcare services for infertility indicates differential access to quality healthcare, especially at the primary care level for initial infertility care [42,65].

This study highlights the importance of a developmental perspective when studying how young people process and negotiate medical conditions that may compromise their fertility. An important finding from our previous research with the same dataset is that entering the emerging adulthood stage of the life course (often defined as ages 18-25) meaningfully shifted some participants' perspectives on pregnancy [64,66]. In this study, these perspectives were further impacted by one's perception of their ability to conceive or carry a pregnancy to term. Indeed, some participants in our study had not even considered parenthood until they were diagnosed with their medical condition, while others reacted favorably to an unplanned pregnancy because it indicated that pregnancy was possible. Previous research with patients with endometriosis [67] and PCOS [33,63] has described how diagnoses of these conditions during adolescence launch consideration of childbearing prematurely, with a few studies noting that some adolescents feel pressured by their healthcare providers to become pregnant "sooner, rather than later" [68,69]. Understanding how young adults process information about medical conditions' impact on their

fertility and change or make plans in response is important in order to best meet their family planning needs.

Strengths of this analysis include the focus on young adults, a developmental period in which actual and anticipated infertility is understudied. Previous research has documented the fertility concerns of women, including adolescents, diagnosed with endometriosis and PCOS and described the distress and uncertainty that is associated with these diagnoses [32-34,40,63,69,70]; our analysis advances the literature by focusing on pregnancy preferences and contraceptive decision-making among young adults. While pregnancy prevention is often the primary family planning concern for young adults, individuals' expectations of compromised fertility can affect their pregnancy desires and contraceptive decision-making, even when it appears they are avoiding pregnancy. This exploratory analysis highlights the value of utilizing the reproductive journey framework, which acknowledges and examines the connections between one's reproductive past, present and future, versus focusing on time-specific, discrete reproductive events [71]. As this analysis emerged organically from the data in a subsample of participants and was not a primary focus of the larger study, the sample size for this analysis is small for exploring the number and diversity of medical conditions experienced by participants [72]. Further, our dataset did not contain extensive information about individuals' medical conditions and health statuses—and their understanding of such—and experiences with healthcare providers that would deepen this analysis, allow for a more interpretive approach, and enable saturation on additional themes. Taken as a whole, health conditions that can impact fertility affect a considerable number of women, suggesting a need for increased attention to and understanding of the complex ways in which they influence contraceptive and pregnancy decision-making. Future research using both quantitative and qualitative approaches to

investigate this phenomenon should focus on individual conditions or recruit a purposive sample that represents a variety of conditions in order to develop specific practice recommendations.

Though this analysis was exploratory, it does suggest that tailored family planning care is needed for young adults with medical conditions or who have undergone procedures that may affect their fertility. For example, a patient who anticipates difficulty with pregnancy may be less likely to disclose that they want to become pregnant, implementing a self-protection mechanism in the event they cannot actualize their desires [62]. Previous research with women and adolescents with endometriosis and PCOS describes an overall lack of effective communication with healthcare providers about fertility, resulting in frustration from already distressed patients and leading to perceptions of complete infertility rather than compromised fecundity [31,33,34,38,40,67]. This may be exacerbated for women of color, owing to the historical and ongoing racism in healthcare settings [45-47,65]. While a brief family planning clinical encounter rarely allows for the time to deeply understand the processes and considerations of every patient, knowing that young adults who anticipate compromised fertility may negotiate contraceptive decision-making and pregnancy planning with great complexity can help providers ask targeted questions, including assessing patients' knowledge of their fertility status and describing potential treatment options. If desired, young people who may face difficulty becoming pregnant should be provided with information about infertility treatments; there is a large unmet need for infertility services in the U.S. owing to lack of insurance coverage, and many infertile women report never discussing treatments with a healthcare provider [73]. While a patient who anticipates compromised fertility may be hesitant to admit their pregnancy desires or plans, being able to understand their openness to pregnancy (e.g., by probing on how they feel and what they might do in the event of a pregnancy) can help determine if either or both pre-pregnancy or

contraceptive care are salient, as well as illuminate the potential need for infertility treatment.

Providing this type of personalized care may help patients develop a more accurate and realistic understanding of their fertility, access the family planning services they need, and foster a sense of trust in their providers.

Table. Demographic characteristics of study participants with medical conditions or procedures who perceived they were infertile (n=12)

Characteristic	Mean (SD)
Age (in years)	21.5 (1.7)
	n (%)
Gender	
Woman	10 (83)
Man	2 (17)
Race/Ethnicity ^a	
Latino/a	6 (50)
Black	3 (25)
Asian/Pacific Islander	1 (8)
White	3 (25)
Multiracial	1 (8)
Educational Attainment	
High school	4 (33)
Vocational or technical training, associate's degree	2 (17)
Some college	3 (25)
College graduate	3 (25)
Parent	5 (42)
Ever pregnant or gotten a partner pregnant	7 (58)
In a relationship for more than 1 year	10 (83)
Medical condition or procedure	
Ovarian cysts	3 (25)
Polycystic ovary syndrome	2 (17)
Endometriosis	2 (17)
Lupus	1 (8)
Low sperm count	1 (8)
Intensive radiology treatment	1 (8)
Complications from previous intrauterine device	1 (8)
Thyroid cancer	1 (8)
Likelihood of infertility or difficulty getting pregnant	
Not at all likely	3 (25)
Slightly likely	6 (50)
Quite likely	2 (17)
Extremely likely	1 (8)

Notes: ^a Participants could identify with multiple racial and ethnic groups, thus the sum of all categories exceeds 100%.

Figure. Holly's Story

Holly is 23-years-old, married, and the mother of an eight-month-old baby. She describes her husband and herself as religious, which underlies her mixed feelings about contraception. She has been pregnant twice, with one miscarriage and one live birth. Holly was diagnosed with PCOS at age 16, following the rupture of an ovarian cyst that sent her to the emergency room. She remembers the messaging she received from doctors surrounding her diagnosis: "I just kept getting told by every single doctor, you're probably not going to get pregnant, or if you do, you're probably not going to be able to keep the baby. So I was like, I'm never going to have children." Throughout her interview, she described the ways in which PCOS has influenced her feelings about pregnancy and her contraceptive decision-making.

At age 17, Holly experienced an unplanned pregnancy; she was not using contraception at the time because she believed that she could not get pregnant. When reflecting back on the ways in which her diagnosis influenced her contraceptive decision-making, she noted that it made her "a lot less quick to use it [contraception]" as she did not want to potentially miss her only chance at motherhood and "trap it in a condom." Holly also described how PCOS shaped her emotional response to learning she was pregnant: "Internally I was ecstatic, because I've always wanted, like that was a dream to have babies." While she acknowledged that she had an, "Oh crap! What the hell am I going to do?" reaction, she also described feelings of happiness for what she saw as a sign that pregnancy would not be impossible for her, despite having PCOS. "And so like the prospect of me being pregnant, I was like, the possibility, it's there. This could happen. I know there's a possibility that I could miscarry, but there's a possibility that I don't, and the fact that I'm even pregnant, it's the first step." Holly eventually went on to experience a miscarriage at 12 weeks, but the pregnancy gave her hope for the future.

Years later, Holly married a different partner, with whom she had a child. She described how her PCOS diagnosis played a role in the way she planned her pregnancy, as well as the decision to stop using contraception. Holly and her partner used the "whatever happens method," in which they were not actively trying to get pregnant or to avoid pregnancy. For Holly, this approach was an alternative to using fertility-awareness based methods (e.g., charting temperatures, timed intercourse), which she felt were unavailable owing to her PCOS diagnosis: "I can't like test my, you know, temperatures and, you know, like all that... So I knew that there was nothing that I could really do there but there was – I could just not use protection, I could just not, and then if I do get pregnant, then great, and if I don't get pregnant, then I'll just keep waiting." She and her husband went on to have a baby and are looking forward to trying to have more children once they are more financially stable.

At the time of her interview, Holly was using an intrauterine device to avoid pregnancy, as she had given birth to her daughter eight months prior. While she did not desire another pregnancy in the near future, she noted that she would be happy if she found out she was pregnant today. Interestingly, her pregnancy plans and contraceptive decision-making no longer seemed to be influenced by PCOS; Holly felt that it was not at all likely that she would experience difficulty getting pregnant in the future. Now, her plans seem to be guided by her financial situation, and her belief that, "If God really wants you to be pregnant, you will be pregnant."

References

- [1] Sirmans S.M., Pate K.A. Epidemiology, diagnosis, and management of polycystic ovary syndrome. *Clinical Epidemiology*. 2014;6:1-13.
- [2] Lizneva D., Suturina L., Walker W., Brakta S., Gavrilova-Jordan L., Azziz R. Criteria, prevalence, and phenotypes of polycystic ovary syndrome. *Fertility and Sterility*. 2016;106:6-15.
- [3] Schrager S., Falleroni J., Edgoose J. Evaluation and treatment of endometriosis. *Am Fam Physician*. 2013;87:107-13.
- [4] Shafrir A.L., Farland L.V., Shah D.K., Harris H.R., Kvaskoff M., Zondervan K., et al. Risk for and consequences of endometriosis: A critical epidemiologic review. *Best Practice & Research Clinical Obstetrics & Gynaecology*. 2018.
- [5] Okoroh E.M., Hooper W.C., Atrash H.K., Yusuf H.R., Boulet S.L. Prevalence of polycystic ovary syndrome among the privately insured, United States, 2003-2008. *American Journal of Obstetrics & Gynecology*. 2012;207:299.e1-e7.
- [6] Azziz R., Woods K.S., Reyna R., Key T.J., Knochenhauer E.S., Yildiz B.O. The prevalence and features of the polycystic ovary syndrome in an unselected population. *The Journal of Clinical Endocrinology & Metabolism*. 2004;89:2745-9.
- [7] Knochenhauer E.S., Key T.J., Kahsar-Miller M., Waggoner W., Boots L.R., Azziz R. Prevalence of the polycystic ovary syndrome in unselected Black and White women of the southeastern United States: A prospective study. *The Journal of Clinical Endocrinology & Metabolism*. 1998;83:3078-82.
- [8] Buck Louis G.M., Hediger M.L., Peterson C.M., Croughan M., Sundaram R., Stanford J., et al. Incidence of endometriosis by study population and diagnostic method: The endo study. *Fertility and sterility*. 2011;96:360-5.
- [9] Laufer M.R., Sanfilippo J., Rose G. Adolescent endometriosis. *Journal of Pediatric and Adolescent Gynecology*. 2003;16:S3-S11.
- [10] Bremer A.A. Polycystic ovary syndrome in the pediatric population. *Metabolic Syndrome and Related Disorders*. 2010;8:375-94.
- [11] Giudice L.C., Kao L.C. Endometriosis. *The Lancet*. 2004;364:1789-99.
- [12] Joham A.E., Teede H.J., Ranasinha S., Zoungas S., Boyle J. Prevalence of infertility and use of fertility treatment in women with polycystic ovary syndrome: Data from a large community-based cohort study. *Journal of Women's Health*. 2015;24:299-307.
- [13] Fourquet J., Sinaii N., Stratton P., Khayel F., Alvarez-Garriga C., Bayona M., et al. Characteristics of women with endometriosis from the USA and Puerto Rico. *Journal of endometriosis and pelvic pain disorders*. 2015;7:129-35.
- [14] Gupta S., Goldberg J.M., Aziz N., Goldberg E., Krajcir N., Agarwal A. Pathogenic mechanisms in endometriosis-associated infertility. *Fertility and Sterility*. 2008;90:247-57.
- [15] Alba P., Khamashta M. Systemic lupus erythematosus and pregnancy. In: Roccatello D, Emmi L, editors. *Connective tissue disease: A comprehensive guide - volume 1*. Cham: Springer International Publishing; 2016. p. 147-58.
- [16] Zullo F., Spagnolo E., Saccone G., Acunzo M., Xodo S., Ceccaroni M., et al. Endometriosis and obstetrics complications: A systematic review and meta-analysis. *Fertility and Sterility*. 2017;108:667-72.e5.

- [17] Roos N., Kieler H., Sahlin L., Ekman-Ordeberg G., Falconer H., Stephansson O. Risk of adverse pregnancy outcomes in women with polycystic ovary syndrome: Population based cohort study. *BMJ*. 2011;343.
- [18] Gemmill A. Perceived subfecundity and contraceptive use among young adult U.S. Women. *Perspectives on Sexual and Reproductive Health*. 2018.
- [19] Polis C.B., Zabin L.S. Missed conceptions or misconceptions: Perceived infertility among unmarried young adults in the United States. *Perspectives on Sexual and Reproductive Health*. 2012;44:30-8.
- [20] Frohwirth L., Moore A.M., Maniaci R. Perceptions of susceptibility to pregnancy among U.S. Women obtaining abortions. *Social Science & Medicine*. 2013;99:18-26.
- [21] Raine T., Minnis A.M., Padian N.S. Determinants of contraceptive method among young women at risk for unintended pregnancy and sexually transmitted infections. *Contraception*. 2003;68:19-25.
- [22] Biggs M.A., Karasek D., Foster D.G. Unprotected intercourse among women wanting to avoid pregnancy: Attitudes, behaviors, and beliefs. *Women's Health Issues*. 2012;22:e311-e8.
- [23] Nettleman M.D., Chung H., Brewer J., Ayoola A., Reed P.L. Reasons for unprotected intercourse: Analysis of the PRAMS survey. *Contraception*. 2007;75:361-6.
- [24] Stevens-Simon C., Kelly L., Singer D., Cox A. Why pregnant adolescents say they did not use contraceptives prior to conception. *Journal of Adolescent Health*. 1996;19:48-53.
- [25] Lundsberg L.S., Pal L., Garipey A.M., Xu X., Chu M.C., Illuzzi J.L. Knowledge, attitudes, and practices regarding conception and fertility: A population-based survey among reproductive-age United States women. *Fertility and Sterility*. 2014;101:767-74.e2.
- [26] Rainey D.Y., Stevens-Simon C., Kaplan D.W. Self-perception of infertility among female adolescents. *American Journal of Diseases of Children*. 1993;147:1053-6.
- [27] White E., Rosengard C., Weitzen S., Meers A., Phipps M.G. Fear of inability to conceive in pregnant adolescents. *Obstetrics & Gynecology*. 2006;108:1411-6.
- [28] Centers for Disease Control and Prevention. Key statistics from the National Survey of Family Growth, https://www.cdc.gov/nchs/nsfg/key_statistics/i.htm - infertility; 2017 [accessed July 9, 2018, 2018].
- [29] Downs J.S., Bruine de Bruin W., Murray P.J., Fischhoff B. When “it only takes once” fails: Perceived infertility predicts condom use and sti acquisition. *Journal of Pediatric and Adolescent Gynecology*. 2004;17:fr0224.
- [30] Wimberly Y.H., Kahn J.A., Kollar L.M., Slap G.B. Adolescent beliefs about infertility. *Contraception*. 2003;68:385-91.
- [31] Young K., Fisher J., Kirkman M. Endometriosis and fertility: Women's accounts of healthcare. *Human Reproduction*. 2016;31:554-62.
- [32] Young K., Fisher J., Kirkman M. Women's experiences of endometriosis: A systematic review and synthesis of qualitative research. *Journal of Family Planning and Reproductive Health Care*. 2015;41:225.
- [33] Weiss T.R., Bulmer S.M. Young women's experiences living with polycystic ovary syndrome. *Journal of Obstetric, Gynecologic & Neonatal Nursing*. 2011;40:709-18.
- [34] Tomlinson J., Pinkney J., Adams L., Stenhouse E., Bendall A., Corrigan O., et al. The diagnosis and lived experience of polycystic ovary syndrome: A qualitative study. *Journal of Advanced Nursing*. 2017;73:2318-26.
- [35] Whelan E. ‘No one agrees except for those of us who have it’: Endometriosis patients as an epistemological community. *Sociology of Health & Illness*. 2007;29:957-82.

- [36] Fauconnier A., Staraci S., Huchon C., Roman H., Panel P., Descamps P. Comparison of patient- and physician-based descriptions of symptoms of endometriosis: A qualitative study. *Human Reproduction*. 2013;28:2686-94.
- [37] Kudesia R., Chernyak E., McAvey B. Low fertility awareness in United States reproductive-aged women and medical trainees: Creation and validation of the fertility & infertility treatment knowledge score (fit-ks)johan. *Fertility and Sterility*. 2017;108:711-7.
- [38] Cox H., Henderson L., Andersen N., Cagliarini G., Ski C. Focus group study of endometriosis: Struggle, loss and the medical merry-go-round. *International Journal of Nursing Practice*. 2003;9:2-9.
- [39] Denny E. Women's experience of endometriosis. *Journal of Advanced Nursing*. 2004;46:641-8.
- [40] Jones G., Jenkinson C., Kennedy S. The impact of endometriosis upon quality of life: A qualitative analysis. *Journal of Psychosomatic Obstetrics & Gynecology*. 2004;25:123-33.
- [41] Chandra A., Copen C.E., Stephen E.H. Infertility and impaired fecundity in the United States, 1982–2010: Data from the National Survey of Family Growth. *National Health Statistics Reports*. Hyattsville, MD: National Center for Health Statistics; 2013.
- [42] Huddleston H.G., Cedars M.I., Sohn S.H., Guidice L.C., Fujimoto V.Y. Racial and ethnic disparities in reproductive endocrinology and infertility. *American Journal of Obstetrics & Gynecology*. 2010;2:413-9.
- [43] Kaplowitz E.T., Ferguson S., Guerra M., Laskin C.A., Buyon J.P., Petri M., et al. Contribution of socioeconomic status to racial/ethnic disparities in adverse pregnancy outcomes among women with systemic lupus erythematosus. *Arthritis Care & Research*. 2017;70:230-5.
- [44] Shade G.H., Lane M., Diamond M.P. Endometriosis in the African American woman—racially, a different entity? *Gynecol Surg*. 2012;9:59-62.
- [45] Haider S., Stoffel C., Donenberg G., Geller S. Reproductive health disparities: A focus on family planning and prevention among minority women and adolescents. *Global Advances in Health and Medicine*. 2013;2:94-9.
- [46] Boulware L.E., Cooper L.A., Ratner L.E., LaVeist T.A., Powe N.R. Race and trust in the health care system. *Public Health Reports*. 2003;118:358-65.
- [47] Roberts D. *Killing the Black body: Race, reproduction, and the meaning of liberty*. New York: Pantheon Books; 1997.
- [48] Gómez A.M., Wapman M. Under (implicit) pressure: Young Black and Latina women's perceptions of contraceptive care. *Contraception*. 2017;96:221-6.
- [49] Breheny M., Stephens C. Barriers to effective contraception and strategies for overcoming them among adolescent mothers. *Public Health Nursing*. 2004;21:220-7.
- [50] Kinsella E.O., Crane L.A., Ogden L.G., Stevens-Simon C. Characteristics of adolescent women who stop using contraception after use at first sexual intercourse. *Journal of Pediatric and Adolescent Gynecology*. 2007;20:73-81.
- [51] Miller W.B. Why some women fail to use their contraceptive method: A psychological investigation. *Family Planning Perspectives*. 1986;18:27-32.
- [52] Weisberg E., Fraser I.F. Contraception and endometriosis: Challenges, efficacy, and therapeutic importance. *Open Access Journal of Contraception*. 2015;6:105-15.
- [53] Joham A.E., Boyle J.A., Ranasinha S., Zoungas S., Teede H.J. Contraception use and pregnancy outcomes in women with polycystic ovary syndrome: Data from the Australian Longitudinal Study on Women's Health. *Human Reproduction*. 2014;29:802-8.

- [54] Holton S., Papanikolaou V., Hammarberg K., Rowe H., Kirkman M., Jordan L., et al. Fertility management experiences of women with polycystic ovary syndrome in Australia. *The European Journal of Contraception & Reproductive Health Care*. 2018;23:282-7.
- [55] Young K., Kirkman M., Holton S., Rowe H., Fisher J. Fertility experiences in women reporting endometriosis: Findings from the understanding fertility management in contemporary Australia survey. *The European Journal of Contraception & Reproductive Health Care*. 2018:1-7.
- [56] Jones G.L., Hall J.M., Lashen H.L., Balen A.H., Ledger W.L. Health-related quality of life among adolescents with polycystic ovary syndrome. *Journal of Obstetric, Gynecologic, & Neonatal Nursing*. 2011;40:577-88.
- [57] Corbin J., Strauss A. *Basics of qualitative research (3rd ed.): Techniques and procedures for developing grounded theory*. Thousand Oaks, California: Sage; 2008.
- [58] Kaye K., Suellentrop K., Sloup C. *The fog zone: How misperceptions, magical thinking, and ambivalence put young adults at risk for unplanned pregnancy*. Washington, D.C.: National Campaign to Prevent Teen and Unplanned Pregnancy; 2009.
- [59] Saldaña J. *The coding manual for qualitative researchers*. 3rd ed. Los Angeles, CA: Sage Publications Ltd.; 2016.
- [60] Braun V., Clarke V., Hayfield N., Terry G. Thematic analysis. In: Liamputtong P, editor. *Handbook of research methods in health social sciences*. Singapore: Springer Nature; 2018.
- [61] Ponterotto J.G. Brief note on the origins, evolution, and meaning of the qualitative research concept thick description. *The Qualitative Report*. 2006;11:538-49.
- [62] Gómez A.M., Arteaga S., Villaseñor E., Arcara J., Freihart B. The misclassification of ambivalence in pregnancy intentions: A mixed methods analysis. *Perspectives on Sexual and Reproductive Health*. 2019;51:7-15.
- [63] Trent M.E., Rich M., Austin S.B., Gordon C.M. Fertility concerns and sexual behavior in adolescent girls with polycystic ovary syndrome: Implications for quality of life. *Journal of Pediatric and Adolescent Gynecology*. 2003;16:33-7.
- [64] Gómez A.M., Arteaga S., Ingraham N., Arcara J., Villaseñor E. It's not planned, but is it okay? The acceptability of unplanned pregnancy among young people. *Women's Health Issues*. 2018;28:408-14.
- [65] Greil A.L., McQuillan J., Shreffler K.M., Johnson K.M., Slauson-Blevins K.S. Race-ethnicity and medical services for infertility: Stratified reproduction in a population-based sample of U.S. Women. *Journal of Health and Social Behavior*. 2011;52:493-509.
- [66] Arnett J.J. Emerging adulthood: A theory of development from the late teens through the twenties. *American Psychologist*. 2000;55:469-80.
- [67] Plotkin K.M. *Stolen adolescence: The experience of adolescent girls with endometriosis*. Doctoral Dissertations Available from Proquest. 2004.
- [68] Facchin F., Saita E., Barbara G., Dridi D., Vercellini P. "Free butterflies will come out of these deep wounds": A grounded theory of how endometriosis affects women's psychological health. *Journal of Health Psychology*. 2018;23:538-49.
- [69] Williams S., Sheffield D., Knibb R.C. 'Everything's from the inside out with PCOS': Exploring women's experiences of living with polycystic ovary syndrome and co-morbidities through Skype™ interviews. *Health Psychology Open*. 2015;2:2055102915603051.
- [70] Washington R.D. *The effect of polycystic ovary syndrome on daily activities, self-esteem and experiences in employment*. Carbondale, IL: Southern Illinois University Carbondale; 2005.
- [71] Johnson K.M., Greil A.L., Shreffler K.M., McQuillan J. Fertility and infertility: Toward an integrative research agenda. *Population Research and Policy Review*. 2018.

[72] Malterud K., Siersma V.D., Guassora A.D. Sample size in qualitative interview studies: Guided by information power. *Qualitative Health Research*. 2016;26:1753-60.

[73] Greil A.L., Slauson-Blevins K.S., Tiemeyer S., McQuillan J., Shreffler K.M. A new way to estimate the potential unmet need for infertility services among women in the United States. *Journal of Women's Health*. 2016;25:133-8.