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Applying the Adaptive Leadership Framework for Chronic Illness to understand how American and British men navigate the infertility process

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Abstract

In this article, we sought to understand the adaptive challenges and work faced by men with male factor infertility. Using a prospective qualitative study in private (the United States) and academic (the United Kingdom) urology clinics, we recruited seven American and five British men with primary infertility after their urology consultation for male factor infertility between December 2015 and April 2017. Individual in-depth qualitative interviews were conducted shortly after male factor infertility urology consultation and then two additional interviews at about 3 and 6 months. We found three themes related to adaptive challenges faced during fertility treatment: avoidance (not disclosing, avoided social network), uncertainty (about ability to have a child, fertility-related information, and male factor infertility status), and affective symptoms (sadness, shock, disbelief, denial, about not achieving fatherhood, and poor outcomes). Four themes about adaptive work included focusing on goal (having clear, actionable steps; knowledge received from urologist; exhausted all options; focus on parenthood), support from partner (relationship and communication), support from health care team (provision of emotional support, increased comfort with staff over time, disclosure of knowing others with same condition), and acquired information (understanding issue, support from urologist, seeking information). We concluded that men with male factor infertility face adaptive challenges including avoidance, uncertainty, and affective symptoms. To manage during the treatment process, they use adaptive work including focusing on the goal, receiving support from their partner and health care team, and acquiring information. Although qualitative results cannot be generalized to larger populations, they might be applicable to men with male factor infertility during infertility treatment.

Keywords

adaptive challenges, adaptive work, anxiety, coping, male factor infertility

Introduction

Few life goals are as central to the human experience as is reproduction and childbirth (Martins et al., 2014). For nearly 15 percent of couples, however, achieving this goal presents challenges due to infertility. Of couples experiencing infertility, a male factor cause is identified in 30–50 percent of cases (Chandra et al., 2013). There is increasing data to suggest that much of male factor infertility (MFI) has an association with specific chronic conditions and disease such as cardiovascular disease and cancer (Eisenberg et al., 2015). Furthermore, because in-vitro fertilization (IVF) using intracytoplasmic sperm injection utilizes minimal number of sperms to achieve a pregnancy

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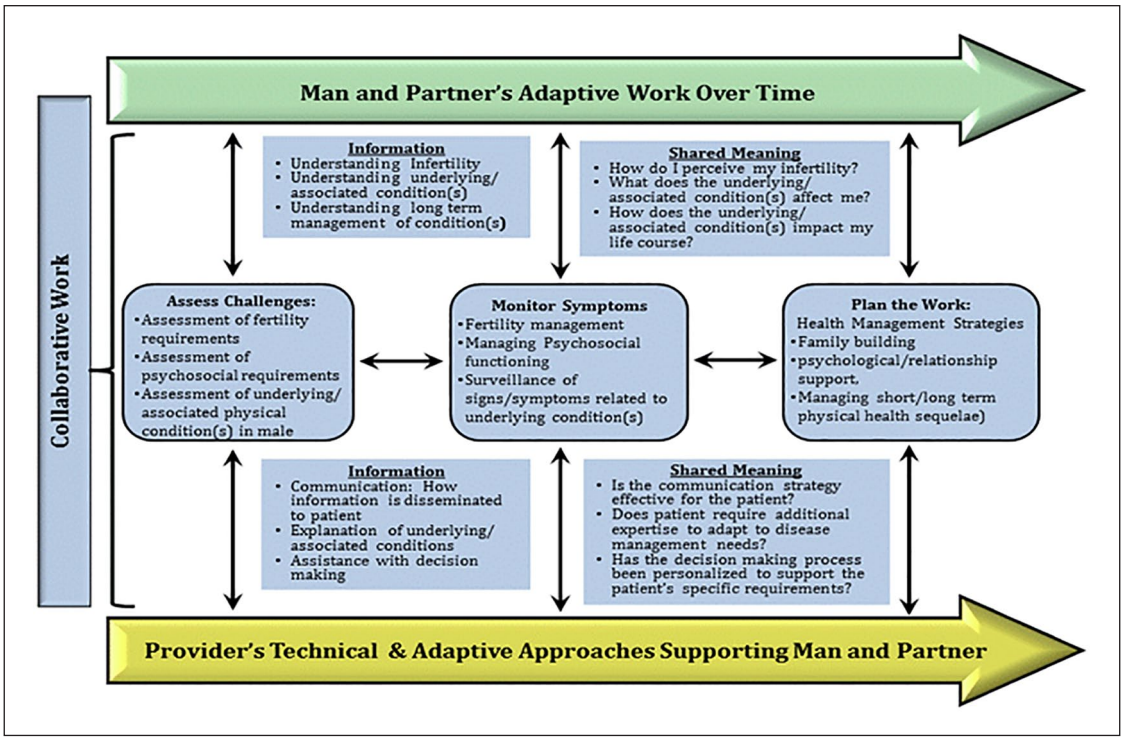

Figure 1. Adaptive Leadership Framework for Chronic Illness.

even when severe MFI is present, the actual cause is rarely diagnosed or corrected.

It is unclear how men diagnosed with MFI navigate the diagnosis and treatment process, and integrate this diagnosis into their daily lives. Such men are more likely to experience psychological challenges that could have an impact on their functioning. For example, men undergoing assisted reproductive treatment (ART) such as IVF have higher levels of depressive symptoms than the national incidence (Li et al., 2013), and infertile men are at a higher risk of sexual dysfunction than fertile men (Ferraresi et al., 2013). Men report increases in distress during the fertility work-up by medical professionals (Pook et al., 2002), and men react differently than their female partners to the infertility diagnosis, very often more negatively (Nachtigall et al., 1992). Feelings like grief and loss can extend past the time a couple is actively attempting family building, particularly if they are not successful (Webb and Daniluk, 1999).

While much of the research about stress and infertility has focused on the female partner, little is known about how men experience the diagnosis and treatment, specifically when a male factor issue is identified. It is critical to understand the male's experience with infertility to develop appropriate interventions to support men diagnosed with MFI and their partners. Despite men "sharing responsibility" with their female partners, the male half of a couple is often marginalized during the treatment process. This can lead to feelings of detachment and uncertainty, similar to their experience with maternity care in which the focus continues to be on the female (Deeney et al., 2012). One study about men going through infertility treatment found that men used language like "overlooked," "ignored," and "bystander" to describe their role (Hinton and Miller, 2013).

The Adaptive Leadership Framework for Chronic Illness (Anderson et al., 2015) recognizes patient-centered care that helps providers not only to address patient symptoms but also to understand the challenges and the work needed to support men through the diagnosis and treatment of male infertility (Figure 1). This framework has been successfully used in other conditions such as diabetes (Carthron et al., 2015), and its applicability to MFI populations has been described (Stevenson and McEleny, 2017). Because many men only discover their MFI issue at the time of their fertility clinical assessment, they have not had to learn adaptive behaviors to help them during the diagnosis and treatment phases. In addition, due to the highly technical nature of the treatment, there can be significant adaptive challenges that go unrecognized. For example, an adaptive challenge arises when men are told they have azoospermia or severe oligospermia, which may challenge a man's self-perception, potentially leading to stress and ultimately impacting negatively the quality of life. Although the framework is useful in understanding both the patient's adaptive work and the provider's technical and adaptive work over time (Figure 1), this study sought to understand the patient's adaptive work only. The aim of this study was to understand the adaptive challenges and work of men with MFI in the period of time following urological evaluation of MFI.

Methods

Study design/participants and procedure

This was a qualitative, longitudinal study designed to identify the adaptive challenges and work of men in the time period following examination by the urologist for MFI in the setting of seeking a pregnancy.

Men seeking consultation from a fertility urologist were recruited following the detection of MFI (from either their primary provider or their partner's gynecologist/infertility specialist who had done the initial testing and made the referral). Inclusion criteria were men under the age of 50, in a partnered relationship with a woman who had been trying without success to conceive a pregnancy, who had been referred due to suspected or diagnosed MFI, and who had the ability to read and write English. Exclusion criteria were having living children, either biological or adoptive, and history of vasectomy. The convenience sample consisted of 10 men (5 in the United States and 5 in the United Kingdom). This study was approved by local ethics committees and all participants provided written informed consent.

Participants were recruited following their urology consultation. The first interview was scheduled (Time 1) within 2 weeks following that visit and participants were also asked to complete a survey to collect demographic data. The Time 2 interview was scheduled for approximately 3 months later, and the Time 3 interview approximately for 6 months after Time 1. All interviews were recorded and transcribed. Interviews were conducted by the same person in each site (E.S. in the United States and E.M. in the United Kingdom); both interviewers conferred prior to and during data collection about how to conduct the interview to ensure consistency, and each used the same semi-structured interview guide, which was developed using the Adaptive Leadership Framework for Chronic Illness and a priori codes.

Data analysis

We used content analysis to code the participants' interviews. Two members of the research team (E.S. and K.M.) individually coded the interview transcripts and made notes about possible latent and manifest codes and themes within the context of the Adaptive Leadership Framework for Chronic Illness. Text data were analyzed using a typology of adaptive leadership developed by Marcus Thygeson and modified for our work (Thygeson et al., 2010). Qualitative analysis progressed in stages: (a) a priori codes, that is, emotional response/threat to masculinity, disclosure of the diagnosis, effect on interpersonal relationships including sexuality, negative impact on self-confidence, self-esteem, information deficit, and lack of supportive environment by provider; (b) for data that could not be coded with a priori codes, new codes were developed to ensure that all case study data were coded; (c) we sorted coded data into categories and subcategories that became the raw units for subsequent thematic analysis; and (d) the raw units of data were condensed into themes and explanations about men's adaptive challenges. E.S. and K.M. reviewed common and recurrent themes across both sites as well as divergent themes between the two sites, definitions and initial decision rules regarding codes, and their relationship to larger themes. These were then discussed by E.S. and K.M. and representative quotes were identified for inclusion into this article.

Results

In the United States, 13 men were approached: 3 men were deemed ineligible (did not meet inclusion criteria), 3 men declined/lost to follow-up (1 did not feel comfortable talking about this topic, 2 did not return consent forms), and 7 men consented to participate. In the United Kingdom, six men were approached: zero men were deemed ineligible, one man declined (did not feel comfortable talking about this topic), and five consented but one was lost to follow-up immediately after the consenting process. The final sample size was 11. Participants were men who had a mix of oligospermia (n = 4) and azoospermia (n = 7), and the average age was 32 years, with a range of 28–39 years of age. All participants were Caucasian. Only one of the 11 participants reported using tobacco. Most men (n = 10) reported moderate alcohol use, with one participant reporting >14 drinks/week. Nine men completed all three interviews (six in the United States, three in the United Kingdom); two completed two interviews (one in the United States and one in the United Kingdom) (Table 1).

Adaptive challenges

Adaptive challenges are defined as problems that are outside of a man's current ability to respond effectively to manage their condition (Anderson et al., 2015). Three themes representing adaptive challenges emerged from the data analysis, including "avoidance," "uncertainty," and "affective symptoms." These themes were present at each time point, with those still not pregnant (n = 8) experiencing these challenges throughout the study period, and those who's partners achieved a pregnancy during the course of treatment (n = 3) and to a lesser extent throughout the treatment period (Table 2).

Adaptive challenge theme 1: avoidance

Time 1 subtheme: not disclosing to network, delaying care (n = 11). The majority of men reported disclosing to a very limited number of people in their personal lives.

> Um, and so obviously you know, we have told very direct immediate family, like my parents, but I don't even feel comfortable telling her parents. Or you know, her siblings, and so you know, we've of course asked for thoughts and prayers as we've been meeting with fertility specialists and even though

Table 1. Demographics.

Education	High school or equivalent	2 (n = 11)
	Bachelor's degree	5 (n = 11)
	Graduate level education	4 (n = 11)
US household incomes	<US$50,000/year	1 (n = 6)
	>US$100,000/year	5 (n = 6)
UK household income	£20,000–£39,999/year	2 (n = 4)
	£40,000–£59,000/year	1 (n = 4)
	>£100,000/year	1 (n = 4)
US	Average time trying to conceive	2.32 years (range = 0.75–9 years)
UK	Average time trying to conceive	2.39 years (range = 1.8–3 years)

Table 2. Adaptive challenges and work themes.

	Theme	Sub-themes: Time 1	Sub-themes: Time 2	Sub-themes: Time 3
Adaptive challenges	Avoidance	Not disclosing to network, delaying care	Not disclosing to friends/family unless for practical reasons (time off for work) continues	Avoidance of friends with children increases since initial visit to urologist
	Uncertainty	Uncertain about ability to have a biological child	Uncertainty of fertility-related information, drove them to seek information from unreliable sources	Uncertainly about MFI status and fertility goals
	Affective symptoms	Sadness about not having achieved fatherhood yet, shock/disbelief/denial about diagnosis, concern/anxiety about underlying diagnosis, distress during fertility exam	Sadness, depression, distress about not achieving fatherhood yet/failed treatment/partners sharing with friends/family	Grieving over no sperm/lack of biological child option for those with poor outcomes
Adaptive work	Focusing on the goal	Knowledge from urology consultation; clear plans of actionable steps helpful to move forward provided hope	Knowledge from urology consultation provided options/ clear plans	Exhausting all options to have biological pregnancy/closure; focus on parenthood
	Support from partner	Relations and communication with partner	Quality of relationship with partner; relationship adjustment because of mutual support	Spousal relationship (communication, care for her emotional needs during treatment and pregnancy)
	Support from health care team	Health care team provided emotional support (UK only)	Comfort with staff because of familiarity associated with repeat visits (US and UK)	Disclosure (US and UK)
	Acquiring information	Understanding fertility issue	Support from urologist	Seeking information

MFI: male factor infertility.

> we do have this surgery coming up it is something that is kind of so personal and private in nature, that we haven't even expressed it to direct family outside of my parents. (US05)

> No one knows, as far as I know, that's close to us. (US02)

Often, they did not disclose because they do not feel friends would understand their experience.

> I just don't feel comfortable talking about it with people . . . It's kind of like sympathy but sympathy because they don't . . . understand the feelings that I've got because, like me mate, he's . . . he's quite happy by himself single. (UK01)

Some men tried to avoid dealing with the situation by consciously not thinking about their problem and delaying decision making. ". . . I always kind of put it off. I think she told more people than I have" (US07). When asked how he was dealing with his situation, he stated he was

> working, just kinda trying to forget about it really [laughs]. . . . my idea is, just forget about it and hopefully when we go back, everything will be fine [laughs]. And then approach the subject of dealing with it in a later date. (UK01)

Time 2 subtheme: not disclosing to friends/family unless for practical reasons (time off for work) continues (n = 7). Even

months into treatment, men tended not to disclose to people in their social circle. One man stated, "Uh that upsets me. I tell her please don't share my information with others. Uh, I think she understands but it helps her talk about more, the um . . . I just try not to tell anybody" (US07). Some were distancing themselves from friends who recently had children, particularly when they were not getting pregnant and their peer group were actively building families. "Yeah, I mean, quite a few of . . . my friends have kids now and, sometimes they do . . . you know, they're away doing stuff. And, it does kind of affect us" (US02). Others would prefer not to disclose but recognized that there were people who may need to know, for example, in order to deal with the logistics associated with treatment. "I mean, I would probably just speak to, maybe, just my direct manager" (UK04).

For some of the men who indicated they did not want to disclose their condition early after the diagnosis, over time, they found that, once they did disclose, others were dealing with similar issues and that brought comfort. At Time 1, US05 stated, "I don't even feel comfortable telling her parents. Or you know, her siblings . . . it is something that is kind of so personal and private in nature, that we haven't even expressed it to direct family outside of my parents." And then later into treatment, this man found that disclosing turned into a positive experience

> I told you about friends that we have that we're close with . . . you know I think they've been in it for much longer than we have, um, and so we're able to be a good support for them, um, I think they have really opened up to us . . . there is kind of a stigma there, but um, so yeah, they were very much relieved to find that they weren't alone in this and so they enjoy being able to talk with us and we in turn are happy to be able to talk with them as well.

Time 3 subtheme: avoidance of friends with children increases since initial visit to urologist (n = 5). The men who had yet to achieve a pregnancy by the third time point continued to distance themselves from both friends with kids and those who they did not feel would understand their situation. "Other people, I didn't feel like . . . they understood or wanted to understand" (US04). Some specially avoided situations that involved children or the discussion of friends' children. ". . . I just don't participate in the conversations . . . I just tend to avoid, like, when people are talking about 'oh kids' and that, I tend to just back away from the conversation" (UK01).

Adaptive challenge theme 2: uncertainty

Time 1 subtheme: uncertain about ability to have a biological child (n = 5). The uncertainty of not knowing whether they would be able to have children was present in men undergoing treatment. "And we just didn't know what we wanted to do so it was, it felt scary, what was our future going to be like?" (US04). While for some, it seemed the biggest fear was the ability to have a child and not the reason for the MFI: ". . . it's not frustrating. It's just you're . . . you're in the dark again and you're not going to know until everything's been done. So you've just gotta kind of go with it and have a bit of faith" (UK02).

Time 2 subtheme: uncertainty of fertility-related information drove them to seek information from unreliable sources (n = 9). Most of the men were advised to undergo complex procedures for which they were uncertain about the preparation, recovery, and outcome. One man stated,

> I recall they kind of assured us . . . so we met with someone like right after we met with Dr. XXX once we kind of decided to go ahead with the procedure and kind of assured us oh, you'll receive a packet in the mail, like don't worry, it'll have all the information and so we were expecting a fairly comprehensive packet and it really did not have very much information at all. (US04)

This led him to seek information from the Internet. Even though men acknowledged that much of the information found on the Internet could be inaccurate/overwhelming, they still desired to seek it out.

> But you . . . I mean, it is something that you do. You do just . . . you panic about something so you look it up on the internet and the next thing you know, you . . . [chuckles] you're . . . you . . . you think you're close to death or something, you know? (US04)

Furthermore, the information they received either was of poor quality in primary care (UK men) or geared significantly toward the female by the partner's physician (US men), which emerged as an important challenge, since these providers were their first point of contact with the health care system in relation to their fertility issue.

> They [primary care provider] didn't go into a great lot of depth to be fair. They just obviously said that the . . . you would be able to do more in-depth tests than them. (UK02)

> . . . we really like the [partner's] doctor that we were working with, she was great, but it also seemed like her sort of defacto approach . . . treating the body a little bit more as a machine then as a thinking feeling person inside of it and what they want. (US04)

Time 3 subtheme: uncertainly about MFI status and fertility goals (n = 6). Uncertainty about the underlying cause of the MFI for some seemed to keep them from being able to move on. This was particularly true for those still trying to achieve a pregnancy or for those who had moved on to other family building options. "Well you can put it to bed a bit more. Rather than, sort of, having the speculation aspect of it" (UK02), and some even a year into the treatment still

struggle with the MFI diagnosis. "I mean, I still get a bit upset about it, thinking about it" (UK01). The uncertainty affected how men mentally prepare for another treatment.

> But it's just the fact it's, sort of, it's always in the back of your mind more that it's going to fail again because it didn't work the last time . . . each time it perhaps chips away a little bit at you. (UK02)

One man who had no sperm and suspects it is related to an old injury, but no definitive diagnosis was made, struggles with not having the outcome they wanted. "It is what it is, there is nothing I can change about it. I can't go back and rewind it, do something different. It sucks" (US01).

Adaptive challenge theme 3: affective symptoms

Time 1 subtheme: sadness about not having achieved fatherhood yet, shock/disbelief/denial about diagnosis, concern/anxiety about underlying diagnosis, and distress during fertility exam (n = 10). Most men reported shock and disbelief or denial about their initial infertility diagnosis. Some reported that they did not believe the first semen analysis (and sometimes second). Three men specifically requested a repeat analysis rationalizing there may have been an error somewhere along the way.

> I was shocked. So I felt, you know, scared, worried, sad . . . but also I felt like I could explain it away by a lot of things. So I could say well, it was likely that I . . . I can't even remember at this point . . . different . . . there were some things . . . I had theories as to what could have been going on and simply, I think either it could have been a weird day for me or it could have been the sample, some sort of study error. (US04)

One man was even in denial until surgery was recommended, stating

> to know that there was something it could be, the procedure and through surgery could be taken care of to help remediate some of the flow, I guess that's when kind of the shock really happened. That was when it was really confirmed, knowing that there actually something that needed to be corrected on my part. (US05)

One man found the whole fertility evaluation to be mentally overwhelming, even after he left the clinic.

> It's like you've been popped like a balloon. I just instantly went pfffhw [deflated] and I just wanted to go home and escape and not think about it. (UK01)

As far as the fertility examination, men in the United States reported feeling marginalized during fertility evaluation, particularly by the reproductive endocrinologist:

> they were like concentrating on the woman. Oh we got . . . this is . . . oh well the woman's fine. And then one sperm test "sorry you got a low sperm count" . . . there's no chance of you conceiving naturally. . . . I'll refer you on. And that was it. (UK01)

Another man stated,

> it [urology exam] was very stressful. I think, he was rushed and kind of backed up as far as appointments, and so I think he was maybe in a bit of a rush to try to catch up on his schedule and I think that didn't necessarily help, help the visit.

He further explained that there was a female medical student present, with added discomfort. "She was present for the exam, and that was very stressful and I wish she hadn't been there" (US03).

Time 2 subtheme: sadness, depression, and distress about not achieving fatherhood yet/failed treatment/partners sharing with friends/family (n = 5). For the men who, at this point, continued to seek treatment, more than half reported affective symptoms including sadness and depression from not achieving success yet and/or having failed treatment. One was "dealing with the depressed feelings by following doctor's orders to take clomid and go from there" (US02). One man had no sperm retrieved during surgery and stated, "when you've got your hopes pinned up on something and you get bad news, it's . . . it . . . it's a bitter pill to swallow" (UK02).

Men were distressed when they learned that their partners had shared the issues within their social circle.

> Cause I've . . . sometimes I feel like, they are too much too . . . they're too involved and they know too much. I think that's just me. I just want to keep private until things are done or thing . . . decisions are made. I just don't want their thoughts or, . . . their thought processes influencing [partner's] decisions. (UK01)

> Uh, that upsets me. I tell her please don't share my information with others. Uh, I think she understands but it helps her talk about more, the um . . . I just try not to tell anybody. (US07)

Time 3 subtheme: grieving over no sperm/lack of biological child option for those with poor outcomes (n = 3). Most (8 of 11) of the men at this time point were still seeking a pregnancy. While many still had options ahead of them, for those who had decided to use donor sperm or move on to adoption (3), they struggled with grief. For one man who was unsuccessful in improving his sperm quality and had to move on to donor sperm, it took him a long period of time to grieve. "Very heartbreaking and I didn't want to do a lot of things, but I think I'm slowly back into doing my normal routine, and doing things that I enjoy" (US07). For some who still have not achieved goals, it continues to stay with them. "I wouldn't say I'm depressed on it, but I definitely, like I mentioned, I think about it very quickly, probably every single day" (US06).

Adaptive work

Adaptive work represents the strategies that men used during treatment to address the adaptive challenges; these were the skills that allowed them to manage and navigate their condition and treatment (Anderson et al., 2015). Four adaptive work themes emerged from the data analysis, including "focusing on the goal," "support from partner," "support from health care team" (UK only), and "acquiring information" (Table 2).

Adaptive work theme 1: focusing on the goal

Time 1: knowledge from urology consultation; clear plans of actionable steps helpful to move forward provided hope (n = 11). Men dealt with the MFI diagnosis by focusing specifically on what they could control, which provided actionable steps. Having options kept them thinking into the future and their goal of achieving a pregnancy.

> Focusing mostly on what we can control, I guess, which is not very much but just, yeah just focusing on the things we can do and doing those and taking those as far as setting up the appointments and things like that and not . . . trying not to dwell I guess. (US03)

Men reflected on having more positive feelings about the process because of taking steps to address their issues: "Well yeah, you've got to because if you come up against a hurdle in life, you can't bury your head in the sand. You've just gotta go for it" (UK02). These actionable steps helped to keep them focused on their goals, particularly when tests found no genetic reason for the MFI, thus providing more treatment options. "So if the results were negative [genetic tests] then that kind of closed that chapter" (US07).

Men wanted information as the reason for the underlying problem, so a solution could be found. "You . . . can't leave things like that. You'd rather know and then you can take some positive attitude and try and solve the problem" (UK02). Having clear steps forward allowed men to have more control over the situation: "I had to choose to accept it and to look forward toward what we could do to change that, if anything" (US05).

Time 2: knowledge from urology consultation provided options/ clear plans (n = 10). Throughout the process, men wanted to move from one step in the process to the next, either because something did not work and they wanted another option to try or a step was successful and they were moving closer to their goal. "Now that we were able to get the sperm and were successful with the first round of IVF here . . . um . . . that is kind of the focus now" (US03) and "I'm kind of relieved that it is a clear decision on the process" (US04).

Men wanted to be given all possible options and move quickly through treatment in order to reach their goal. For one man, this meant being able to move on quickly to donor sperm after his unsuccessful surgery, stating

> being offered the donor and everything straightaway, it . . . it . . . it's giving you information. So, then fair enough if you decide on the day not to do it then that's up to you. But it's good to have everything there so you know exactly what your options are. (UK02)

Time 3: exhausting all options to have biological pregnancy/ closure; focus on parenthood (n = 10). For those unable to achieve biological paternity, focusing on alternative approaches to family formation helped focus them on the goal of parenthood. "You're sort of thinking that, if this doesn't work that there's still other options out there for you to become a family" (UK02). For the man who had failed surgery and donor IVF, goal setting (adoption at this point) kept him coping. "Deal with these emotions by just staying focused to the future and having goals" (US01).

Despite significant challenges, there was still a feeling that all options needed to be exhausted, even if that was at significant personal financial expense that ultimately did not result in a pregnancy. Having many treatment options helped men feel that everything could be done. This provided men for whom there was no positive outcome a sense of closure. For one man who exhausted all options and had moved on to adoption, he stated,

> If I wouldn't have done it, I wouldn't have known what my situation was. So I mean, everything I went through sucked but, I wouldn't have known unless I'd done it so . . . there's closure and we did everything we could do. (US01)

Adaptive work theme 2: support from partner

Time 1: relations and communication with partner (n = 6). Most men saw their partners as a significant source of support throughout the process and that the process brought them closer. This support came from talking about the process and supporting each other through the evaluation and decision making.

> It's probably brought us closer as far as having to talk about these things and having to just talk through it and just know that we're both in it together, and that we're gonna support each other however we can as we work through it. (US03)

> I feel like our relationship has come out stronger from it. (US05)

> But I mean, we . . . we . . . we support each other so we . . . we do whatever it takes to get where we need to be. (UK02)

Time 2: quality of relationship with partner; relationship adjustment because of mutual support (n = 7). Men acknowledged that communication during this process helped their relationship and made them a stronger couple. One couple explored fertility issues many years ago, but, because of school and money, did not pursue again until recently. "I think it brought us together, because we've been more open about it this time I think . . . or more . . . on top of it

than the last time" (US07). Another found that the mutual goal helped increase communication and therefore their relationship. "I think it made it stronger, we communicated more and really had to circle the wagons and you know team up and you know, decide what we're going to do, so" (US01). And some use laughter to reduce the stress they are experiencing during the process: "We usually just take the mick out of each other, have a good laugh" (UK02).

Time 3: spousal relationship (communication, care for her emotional needs during treatment and pregnancy) (n = 6). Most of the men report that their relationship with their partner improved during this process, regardless if they achieved a pregnancy or not. Whether there was a pregnancy or not, the majority of men reported that, over time, their relationship was better than before the MFI diagnosis. "It made us stronger. She had to take care of me and she was there for me" (US01). Others specifically cited that MFI helped in this process. "It allowed us to share some of the responsibility" (US02).

Adaptive work theme 3: support from health care team

Time 1: health care team provided emotional support (the United Kingdom only) (n = 3). Men in the United Kingdom found emotional support from their health care team, particularly their urologist, who was embedded in a fertility clinic versus a stand-alone urology clinic like in the United States. "He was very frank and very to the point but friendly and very approachable" (UK03). "Yeah, we need to get this sorted out. We'll . . . we'll get you booked in as soon as we can. So, like, I . . . I feel like it's been a lot more positive and a lot more help than what the . . . the urologist at the local hospital was with us" (UK04). This theme was not found from the interviews with the US men.

Time 2: comfort with staff because of familiarity associated with repeat visits (the United States and the United Kingdom) (n = 3). While some initial interactions with the urologist may have been awkward, particularly related to the physical examination (an affective symptom), repeated interactions improved over time, and their trust increased in the care they were receiving. "Definitely improved and we felt more comfortable going to those appointments with him and trusting him to do the surgery and all of that" (US03). The majority of men of the United States seemed to like the direct style of information delivery. "He was very direct. I appreciate that because I mean he was pretty open, he told us you know if this works, then we can move this forward, if it doesn't work then there is no reason to see me anymore" (US07). Support from the clinical staff have helped men with their adaptive work, "As you got to know the staff a bit better, that the . . . the visits became a little bit easier" (UK04).

Time 3: disclosure (n = 4). Sometimes knowing others were experiencing similar challenges was helpful. "I guess always seeing the low testosterone commercials on TV . . . to know it is a common thing for men to go through" (US07). Providing reassurances of how common their diagnoses are can be in contrast to the previously held beliefs.

> I mean I got the whole sterile thing that I could potentially not produce semen, but it looks like, you know, I didn't know how rare it was, but I thought it seemed somewhat rare. At least from what I've heard. Dr. XXX did say probably 1 in 10 guys that walk in had the same kind. (US01)

Adaptive work theme 4: acquiring information

Time 1: understanding fertility issue (n = 7). Many of the men went into their initial appointment with the urologist unsure of what was happening. They were referred from either their partner's physician or their general practitioner (GP), and were not given much, if any, information other than results from a poor semen analysis. Thus, most turned to the Internet in the hopes of finding more information and unfortunately only served to increase confusion. One man said he was "all over the board, I mean, just googling azoospermia, there's of course a number of different things that could be the cause of it" (US04), and "Maybe it helped a little just to have some idea of what could be going on but probably more than anything, yeah, overwhelming because then of course we don't, all the information is out there but there is no real guidance obviously" (US03). Being presented accurate information helps men make decisions and allow them to feel control in their care. "Once you start getting the facts and figures and everything in front of you, it . . . it becomes easier. The more information that you receive, the clearer it becomes about making a decision . . . you . . . you . . . you get a clearer picture" (UK02).

Time 2: support from urologist (n = 6). Information seemed to help men throughout the process. This was true for some in terms of determining the underlying cause, even when their sperm was found surgically and there were new options to increase chances of success.

> I'm kind of torn . . . in that I really want to know what is going on and why things are the way they are, but at the same time, I don't . . . if it's not going to be a health issue for me in the future then I don't necessarily want to go under again, have surgery again and then, especially considering what happened last time . . . blockage, um and I mean that, I'm torn, still is a little difficult to deal with not knowing and just the thing that is how it is. So I mean I guess I have as much understanding as I could without the surgery. (US03)

The urologist providing information helped decision making for some of the men.

> Being offered the donor and everything straightaway, it . . . it . . . it's giving you information. So, then fair enough if you decide on the day not to do it then that's up to you. But it's

> good to have everything there so you know exactly what your options are. (UK02)

Time 3: seeking information (n = 5). Seeking information about their treatment options, success rates associated with those options, logistics, and how to increase success helped men manage their diagnosis and decision making. This was particularly true when the information was coming from the urologist, though they may have preferred further opportunity to get this information. "Quality of the information is adequate in my opinion, just the time always seems to be really rushed" (US02). In the United Kingdom, patients are always referred to the nurse counselor who can provide addition information during the process, helping the decision making. ". . . we have had an appointment with them and that put a few things to rest as well" (UK04).

Discussion

Adaptive challenges

The Adaptive Leadership Framework for Chronic Illness that guided this study proposes two types of challenges, adaptive and technical, each resolved in different ways. Adaptive challenges were the focus of this article; technical challenges represent the possible treatments for the MFI, coordinated by the health care team. The adaptive challenges involved complex problems that could not be solved by a clinician but rather the patient who must be able to recognize the problem and determine a reasonable solution. In this study, men experienced three adaptive challenges.

All the men, regardless of whether they were pregnant by Time 3 or not, dealt with adaptive challenges; however, they were consistently discussed in interviews among the men still seeking fatherhood, versus those who's partners were pregnant. The adaptive challenges for these men included avoidance, uncertainty as to whether it would work out for them, and affective symptoms associated with not achieving a pregnancy yet (sadness, distress, depression), which may lead to psychological maladjustment over time (Martins et al., 2016).

Men in this study avoided both sharing their MFI situation with those around them and circumstances that placed them with people who were being successful in building their families. For most, there were different levels of disclosure to the partner (most partners were fully aware of his status throughout treatment), less disclosure to family, and significantly less or none to friends and work colleagues. In earlier work, men with MFI reported high levels of stress when having to share the difficulty of becoming pregnant with parents/in-laws and friends (Gradvohl et al., 2013). Avoidance placed men at greater risk for negative psychological outcomes such as depression (Martins et al., 2014). This avoidance is often related to the feeling of being stigmatized about their infertility because of the perception of being masculine deficient (Arya and Dibb, 2016; Bechoua et al., 2016). When men feel acknowledged, both by the medical team and family, they may be more likely to disclose their fertility status and treatment experience (Arya and Dibb, 2016). Furthermore, while the stigma of MFI keeps men from sharing with their social circle, some come to discover the benefit of doing so, either for their own support or being able to support others through the process. Sharing personal experience about infertility can help people cope better with the complex emotions, and if men cannot do this with their immediate social network, then other opportunities such as message boards may be beneficial (Bechoua et al., 2016)

Of the 11 men in this study, 8 were still in active treatment (to genetic, biological, or adoptive parenthood) and 3 were pregnant. Over time, those still in treatment experience continued adaptive challenges than those who were pregnant. In addition, uncertainty changed over time; uncertainty at Time 1 was about being able to have a biological child; at Time 2, it included uncertainty about fertility information as this was when the majority of men were actively engaged in fertility treatments (surgery, intrauterine insemination (IUI), IVF). By Time 3, many of the men had unsuccessful treatment cycles, so uncertainly about MFI status and their fertility goals were expressed again as they looked to the future.

Data suggest that men exhibit more maladjusted psychosocial behaviors with longer treatment (Johansson et al., 2010). Our data and others suggest that health care providers should actively involve men during the treatment process, and consider using coping skills and communication training as an adjuvant of fertility treatment. While we did not specifically ask about this in our study, counseling and/or peer support might be a significant support for many of these men as they navigate this process, particularly for those demonstrating increasing adaptive challenges. The health care team could assess these changes over time making appropriate recommendations to counseling.

Adaptive work

In the adaptive leadership framework, adaptive work is the strategy that men used during treatment to manage and navigate their condition and treatment. In order for adaption to occur over time, collaborative work with others is needed. Relationship development and management are significant parts of this collaborative work (Anderson et al., 2015). In the case of men with MFI, the collaboration can be with both the clinical team and their support system, who support them logistically as well as emotionally.

The findings of this study show that in the context of adaptive work, receiving accurate information about treatment options throughout the process, particularly from the urologist, was important in order to manage their fertility issues. Partnership with the care team is essential and

supported in other literature in which men have reported wanting written information about both practical and emotional components of treatment (Read et al., 2014). In addition, the quality of the relationship through the support of their partner seemed to improve over treatment time with our sample. The quality of life of men going through infertility may be directly associated with their level of marital satisfaction (Keramat et al., 2014). High levels of infertility-related stress levels before initiating fertility treatment can negatively impact the quality and longevity of partnered relationships (Martins et al., 2014); thus, assessing relationship quality and making appropriate referrals as needed are essential parts of the care plan during fertility treatment.

Men in this study used adaptive work to address challenges by having actionable steps in their treatment, which included actively seeking information about their treatment options. In order to manage challenging situations, men made conscious choices about when or how to take action about their situation, instead of reacting to the problem (Fogarty et al., 2015). Psychological flexibility is the ability to be present and use behaviors that are adaptable. This type of flexibility has been shown to improve many aspects of psychological well-being, and may be a component of this adaption in our sample (Hayes et al., 2006). That said, with the significant variation of the quality of information available outside of the health care system, health care providers need to recognize the potential for misinformation and unrealistic expectations for treatment goals. Offering choices and empowering men to select is the best approach, rather than giving limited choices supports a holistic patient-centered approach during consultation visits.

Strengths/weaknesses/future directions

This study has followed the consolidated criteria recommendations for reporting qualitative research (Tong et al., 2007). One of the key features of this research team was the multidisciplinary nature, consisting of both clinical and research nurses, as well as urological medicine. This allowed us to have an understanding of the population of interest from the start of the study inception through study design and data analysis. Furthermore, our informed backgrounds allowed the study team to critically challenge presumptions when arriving at consensus during data analysis. Using two study sites with similar availability of resources but different payment structures for fertility care (the United States versus the United Kingdom) allowed diverse experiences and decision making. However, the majority of the men lived in the same two areas (a small metropolitan area of the US South and a city in Northern United Kingdom); thus, different narratives may have been captured if participants from other parts of the United States and the United Kingdom were included. That said, the majority of findings were consistent in both the United States and the United Kingdom, thus providing some interesting comparisons between the experiences of men during infertility treatment in two different cultures and payment structures. Also, another strength was the prospective longitudinal design of the study, allowing the team to follow men in real time throughout their experience with fertility treatment.

Going forward, areas to be explored would be ways to address the adaptive challenges identified during this study. While we included men with both azoospermia and oligospermia, our analysis did not allow us to see potential differences in experiences based on diagnosis, therefore would be worthy of future investigation. Also, because many of the men do not disclose to their social network while also finding it comforting when they discovered others are going through similar experiences, providing opportunities for men to connect in novel ways encourage the social support men very much need during this challenging time.

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Author contributions

ELS, KM, and DB designed the study and constructed the interview guide. ELS and EM interviewed the participants. ELS and KM performed the analysis, and DB and EM helped with interpretation of the results. KM, EM, and DB participated in the writing of the manuscript and approved the final version.

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