

Exploring the psychological implications of infertility among IVF parents in Uganda using the transactional theory of stress and coping

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Title: Exploring the psychological implications of infertility among IVF parents in Uganda using the Transactional Theory of Stress and Coping.

Short title: Experiences of Infertility among IVF Parents in Uganda

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Abstract

Introduction: Infertility is on the rise among couples of reproductive age globally. In Uganda, while the prevalence of infertility has varied in recent studies due to differences in definitions and measures used, there is growing evidence for risks faced by those directly affected. The experiences and impact of involuntary infertility among the affected individuals and/or couples in Uganda have however not been extensively examined. This study examined the experiences of infertility before a decision to do In Vitro Fertilization (IVF) among individuals or couples who successfully had children through IVF treatment in Uganda.

Methods: In this qualitative phenomenological study, we conducted individual in-person or virtual audio-recorded in-depth interviews with eight participants (one couple and six spouses). Audio recordings were transcribed verbatim and transcripts thematically analyzed. **Results:** Four themes

emerged: 1) Personal and social expectations 2) Frustrations with seeking help, inconclusive medical tests and delays in diagnosis 3) Stigma from family, workplace and community and 4) Psychological and emotional effects of infertility. These themes show growing distress due to failure to have normal conception as per personal and societal expectations. Finding care and the delays in diagnosis were frustrating for participants. Participants' emotional and mental health problems resulted from a combination of factors such as unmet expectations of early conception; stigma and challenges with care and diagnosis. **Conclusion:** The stress that comes with delays in conception is exacerbated by a prolonged search for possible causes of ongoing infertility and diagnosis. A socio-cultural environment that espouses traditional beliefs and expectations about normality of conception increases risks of stigma and serious emotional and mental health problems among individuals facing infertility in Uganda. Public health campaigns on negative beliefs about infertility can reduce the psychological impact on affected individuals and couples.

Key Words: Infertility; Expectations; Stigma, Challenges with care; emotional and mental health impact, Experiences.

Introduction

The World Health Organization (WHO) defines infertility as a disease of the male or female reproductive system characterized by failure to achieve a pregnancy after 12 months or more of regular unprotected sexual intercourse (1). As of 2021, the global prevalence of female and male infertility was 101.1 million (2) and 55 million (3) respectively. The actual prevalence of infertility in Uganda remains unclear. For example, recent pooled analyses reported 6.4% overall infertility among women, with a higher prevalence of secondary infertility compared to primary infertility (4). Additionally, a hospital based study reported 5% infertility among women actively seeking fertility care (5) while a general population survey showed 14.7% prevalence

among women trying to conceive (6). These discrepancies in the prevalence of infertility might be due to variations in definitions and measurements used in individual studies (4-6).

In recent decades, male infertility linked to changes in temperature has been reported globally (7). Sexual dysfunctions such as reduced desire and erectile difficulties are the other known factors associated with male infertility in Uganda (8). Among women, infertility has commonly been attributed to polycystic ovary syndrome (PCOS), ovarian insufficiency, tubal blockage, endometriosis, and intrauterine adhesions (5, 9). However, how Ugandan women in particular and couples in general experience infertility due to these and other possible contributing factors (10-14) has not been extensively documented. A few studies have focused on infertility prevalence and associated factors (4-6) and general experiences of infertility among individuals seeking care (15).

Stigma has been reported alongside other psychosocial and mental health consequences of infertility. For example, social and self-stigma experienced by women with infertility can impair their psychosocial well-being and self-esteem (16). A recent systematic review reported a 64% prevalence of infertility stigma in Africa with a call for urgent interventions (17). Additional effects of infertility on those who experience it were psychological, behavioral, relational and other health related consequences (17). Most of the studies on infertility in Africa especially those examining the psychosocial effects have come from the western and southern parts of the continent (18) with East Africa largely underrepresented despite being part of a bigger geographical area previously referred to as the infertility belt (19). Moreover, the nuanced differences in cultural beliefs across Africa could influence the broader experiences of infertility and its effects among individuals and couples who experience it. We note that very few past studies in Africa focusing on the psychosocial effects of infertility have involved men or couples

(18). Even fewer have reported on experiences of infertility among individuals or couples who eventually had children through Assisted Reproductive Technologies (ART) (17). The lack of interventions focusing on the effects of infertility, such as stigma, implies that affected individuals in regions where stigma is widespread continue to face its psychological consequences. The actual individual and couple experiences, especially psychological, among the affected population have not been widely documented in Uganda. The implications to fertility care and mental health of the affected individuals is thus scanty.

Women who experience infertility face higher risks of stress (20). Despite a recent decline, Uganda's total fertility rate is still higher than the global average (21). Infertility stress in Uganda could therefore be attributed to both societal pressure to have children and the stigma resulting from inability to have children, among other factors. The effects of stress could however depend on how affected individuals appraise and/or cope with ongoing intrapersonal and societal stressors. In this study we attempt to demonstrate how the transactional theory of stress and coping may be applied to further our understanding of nuanced experiences of infertility, a potentially major stressor among affected individuals and couples. Our findings could have policy and practical implications for fertility care and support of women and men facing infertility.

The Transactional Theory of Stress and Coping.

The Transactional Theory of Stress and Coping and the extensions made by Folkman and Moskowitz (22) provide a framework to understand the interaction between the environment and the individual, and possible outcomes. Two key concepts of the original transactional model are cognitive appraisals (primary and secondary) and coping: problem focused coping and emotional focused coping. Stressful events are products of person-environment interactions (23) where

stressors within the environment are appraised by an individual in any one of three different ways: threatening, challenging or harmful. The distress resulting from such appraisal of stimulus triggers coping strategies to either manage the emotions associated with stress or address the stressor itself. Concurrently, the individual evaluates environmental threats or stressors (primary appraisal) and assesses own capacity to change the situation and manage the associated emotional reactions (secondary appraisal) (24).

Additional work by Folkman and Moskowitz (22) on the meaning focused coping and positive psychological states has been widely discussed by Biggs and others (24) and Wethington and others (25). The impact of the external stressor depends on the individual's appraisal of the event as influenced by personal values, goals, beliefs, and environmental factors and resources (24, 25). Psychological well-being resulting from problem solving and emotional regulation (25) is especially important for long-term stressors such as infertility. The original transactional model was recently applied in a study focusing on vaginal fistula among refugee women in Uganda (26), and among women dealing with infertility in Portugal (27). As part of an exploratory study in Uganda, we retrospectively examined the experiences of infertility among individuals or couples who have successfully had children through IVF. This paper focusses on the experiences before the decision to do IVF.

Methods and Materials

Study Design

This qualitative study employed a phenomenological design to explore the participants' in-depth experiences of infertility. We employed the Consolidated criteria for Reporting Qualitative Research (COREQ) checklist (28) as shown in the following sections. According to Aspers and Corte (29), qualitative research refers to the iterative process leading to improved

understanding of new important distinctions resulting from closer proximity to the phenomenon under study.

Population

Our study population consisted of individual spouses or couples in Uganda who have had at least one successful IVF cycle in the last five years. Recent estimates show that the central region in general and Kampala, the main city in particular have the highest number of IVF clinics in the country (4, 30).

Sample Size and Sampling Strategy

Eight participants took part in this study. Following unsuccessful efforts to recruit potential participants from IVF clinics in Kampala, we employed both purposive and snowball sampling through individual referrals and a study information leaflet. The first three participants (a couple and one spouse) were referrals from individuals who saw our study leaflet. Purposive sampling involved making specific decisions to choose individuals with the requisite experiences and willingness to participate as per our study objectives (31). Snowball sampling, on the other hand, was employed as one of the most popular techniques for gathering data about populations that are difficult to reach, given our limited prior interactions with the target group (32) through one of the first three participants' own personal networks.(33). The rest of the five participants were all referred by one participant from their social network. Therefore, after extensive efforts through informal sources, 18 potential participants were contacted, but only eight described above accepted and took part in this study. Ten potential participants did not respond to our follow up text messages, calls and emails after showing initial interest and sharing their contact information with AIM. The reasons for declining, though not explicitly stated, could be

associated with the stigma and sensitivity associated with the phenomena (34) under investigation.

Inclusion and Exclusion Criteria

Individual spouses or couples aged at least 18 years, residing in Uganda, who had successfully completed at least one IVF cycle with a live baby and were willing to take part in an audio-recorded interview in either English or Luganda were eligible to participate in this study. Exclusion criteria included non-Ugandans, Ugandans currently living outside the country and those unwilling to be interviewed. This aligns with the transactional model used throughout data collection, interpretation and discussion of the results.

Data Collection

Recruitment of potential participants started on September 02, 2024. Audio-recorded face to face in-person (three participants) and virtual (five participants) in-depth interviews were conducted between January 13 and May 21, 2025 by AIM, a graduate Clinical Psychology student, to enlist participants' first-hand accounts and reflections on their experiences of involuntary infertility. The interviews lasted between 45 minutes and one hour 15 minutes in a venue and time determined by the participant. No follow up interviews were conducted. An in-depth interview is a qualitative research method for conducting interviews with a limited number of participants to gather deep information about their experiences, perspectives and motivations (35). An interview guide available in the supplementary file, was specifically developed for this study. The overarching question which guided the interview was "Tell me about your experiences before your decision to do IVF". Through this broad research question, we sought each participant's reflections about their experiences of infertility in their natural social environment in line with the transactional theory of stress and coping. Additionally, we chose to

do individual interviews with each spouse (participant) to allow for openness on sensitive issues that could arise from varying personal experiences of infertility. All interviews were conducted in English.

Data Management and Analysis

The audio recording of each completed interview was transcribed verbatim and transferred to specific folders on an encrypted and password-protected laptop accessible by authors only for confidentiality purposes. Code book inductive thematic analysis (TA) following the six steps provided by Braun and Clarke (36) was done by SO, a clinical psychologist who, together with AIM, conceptualized the study. Validation of the codes and the inductively emerging themes was done in iterative discussions involving all authors. The back-and-forth discussions of analysis process together with robust data collection procedures described above enhanced trustworthiness of the study and its findings. All participants were given opportunity for member checking but only two female participants gave feedback on their respective interview transcripts and the data analysis report. These processes enhanced accuracy and credibility of the findings reported in this paper.

Ethical Considerations

The AIDS Support Organization (TASO) Research Ethics Committee granted ethical approval (TASO-2024-398) in accordance to the Uganda National Council of Science and Technology (UNCST) guidelines. AIM contacted all potential participants by phone, shared information about the study and invited them to take part. All participants signed a written informed consent form. To ensure privacy and convenience, participants chose the interview venue and type –physical or virtual. Distress during the interviews was catered for by only continuing with interviews when participants were emotionally stable. One participant needed

two breaks and verbally consented to continue with the interview when emotionally calm.

Information about available psychological support was shared with women who showed distress during the interviews but none of them got in touch for further help. Anonymity and confidentiality of interview data were achieved through removing all identifiers and limiting access to transcripts to only the study investigators.

Results

[INSERT TABLE 1 HERE]

Table 1: Participant Sociodemographic Information

Participant Pseudonym	Gender	Age	Marital Status	Employment Status	Duration of Marriage (Years)	Duration of Infertility (Years)	Underlying condition
Sarah	Female	37	Married	Employed	9	2	Polycystic Ovary Syndrome (PCOS)
Amina	Female	28	Separated	Stay-at-home parent	5	2	Endometriosis
Rebecca	Female	41	Married	Employed	5	3	Tubal factor infertility
Hannah	Female	42	Married	Employed	18	13*	Unexplained infertility
Daniel	Male	45	Married	Employed	18	13*	Unexplained infertility (spouse, Hannah)
Olivia	Female	40	Married	Employed	12	2	Oligospermia (spouse)
Grace	Female	37	Married	Business	8	2	Polycystic Ovary Syndrome (PCOS)
James	Male	49	Married	Business	10	5	Tubal factor infertility (spouse)

*Secondary infertility

Eight parents aged between 28 and 49 years, six females and two males, participated in this study. Six participants reported primary infertility while one couple experienced secondary infertility. Duration of infertility (time participants reported actively trying for a baby) ranged between two to 13 years. The interviews happened within five years of having a baby through IVF. One participant had separated following delivery. The themes in the next section are presented using the transactional theory of stress and coping as a lens for a broader context of interpreting the results. We use pseudonyms throughout the presentation of our findings to maintain the anonymity of the participants.

Personal and social expectations.

This theme shows beliefs and expectations participants individually held in conformity to the broader society regarding conception in marriage. Interpreted through the transactional theory of stress and coping, this theme reflects interactions between individual (participant) and their environment. Three subthemes are highlighted: expectations for normality of conception; explanations for delayed conception; and distress about ongoing struggle with conception.

Expectations for normality of conception

For many of the participants of the current study, marriage was a socially constructed rite of passage to start having babies. Conception early in marriage was thus widely expected by individual couples, their immediate families, and the communities to which they belonged, such as church, work, and neighborhood. For some couples, this was *“as soon I think like in honeymoon, we expect to get out of honeymoon pregnant.”* (Rebecca 41-year-old female). This showed shared individual and social environment interactions. Worries contrasting with these initial expectations gradually became noticeable *“when I saw my friends getting pregnant so fast, I used to wonder what’s wrong with me? I am also doing everything right”* (Grace 37-year-

old female). These concerns were reported by the participants irrespective of gender or fertility history.

“When you get married, you expect children to come. We were together for about 7, 8 years without a child. So definitely, we hoped it would happen normally, but it didn’t.”

(James, 49-year-old male).

“We had two boys before, I thought another child would come when I wanted, but it did not happen... for 13 years” (Hannah, 42-year-old female with secondary infertility).

Explanations for delayed conception

As part of the meaning focused coping, initial individual reasons for delayed conception such as the *“girl has just finished Campus [University], she is not even married, so that was an excuse we had, which was okay.”* (Sarah, 37-year-old female) turned into introspection as the participants reflected on a previously distant possibility of infertility.

“At first, we didn’t want to accept that it could be a fertility issue. We thought maybe the timing was off or stress. You know, those usual things people say.” (Daniel, 45-year-old male with secondary infertility).

For our youngest participant, difficulties in conception might have been anticipated since menarche due to her underlying complex health situation.

“Yes, my spouse was okay, but it was me who was having a medical issue. I had blocked tubes, hormonal imbalance since my childhood, my very first period, then I also have PCOS, that is Polycystic Ovarian syndrome. I think then I also had endometriosis, I had fibroids in and outside of the uterus, and I also had cancer tissues that were forming”

(Amina, 28-year-old stay-at-home parent)

Distress about ongoing struggle with conception

This subtheme shows initial distress following participants' primary appraisal of own interactions with their environment regarding failure to conceive. Concerns reflecting individual/couple transactions with self and their social environment became important stressors. Distress seemed evident as participants' abilities to cope with continued difficulties waned.

"Even these girls, my bridesmaids, are not officially married... here they are conceiving. And for me, I am not conceiving. God, what is this?" (Olivia, 40-year-old female)

"We had started experiencing a bit of depression, a bit of anxiety, a bit of stress with the whole thing... it could be something more severe than we are looking at." (Sarah, 37-year-old female)

"Just all those years you're trying; you're seeing somebody; you realize things are not working... There were some issues like during some menstrual periods, complications, which was an indicator that there was something wrong" (James, 49-year-old male)

Amidst growing distress, a male participant reported that even his gestures of understanding and support to his wife could not completely mitigate the pain that came with suspected infertility.

"I would say it was somehow disturbing, because at one time she would talk about it then I would keep saying no, there is nothing you can do about it, if that's what God has chosen then let it be. ... Since I'm not complaining then she should not worry about it but somehow I would see it stressing her somehow, yeah." (Daniel, 45-year-old male)

Frustrations with seeking help, inconclusive medical tests and delays in diagnosis

This theme characterizes the distress arising from interactions between individuals and the health care environment. Three subthemes emerged: exploring traditional causes of infertility and remedies; frustrations with inconclusive results and delays in diagnosis; and confirmation of infertility and initial reactions showing various types of coping.

Exploring traditional causes of infertility and remedies

This subtheme highlights problem focused coping. For some participants, infertility was individually and communally attributed to unfinished marriage ceremonies. Spiritual and traditional rituals, such as responsible elders praying for the affected couple, were therefore considered viable problem-focused coping strategies to ensure conception happens.

"I started telling myself I was cursed...So we go traditionally... maybe it could be traditional." (Rebecca, 41-year-old female).

"We went to the elders... maybe the dowry wasn't finished... then he got the money, cleared the bride price, they prayed for us... but still there was nothing." (Amina, 28-year-old female)

One of the female participants, out of growing despair and perhaps suspecting that husband factors might be responsible for their ongoing struggles with conception, reminisced, *"I even thought of going back to my ex just to see if I could conceive. That's how desperate I was."* (Olivia, 40-year-old female). Such measures depict emotional rather than problem focused coping.

Frustrations with inconclusive results and delays in diagnosis

In part because of already existing distress associated with dashed hopes and expectations of normal conception, participants found their medical investigations very frustrating. From one health facility to another, they reported undergoing several tests and examinations in search for the

cause of their delayed conception. For some, the initial medical tests either revealed nothing or showed seemingly innocuous conditions. These experiences compounded negative primary and secondary appraisals thus exacerbating their distress.

"They checked him, everything was okay. They checked me, everything was okay... but still we were wondering why we were not conceiving" (Hannah, 42-year-old female with secondary infertility).

"I was treated for ulcers, then malaria, then told my hormones were the issue. But no one really said what exactly the problem was." (Olivia, 40-year-old female)

From the initial tests, efforts to find the cause were characterized by inconclusive results from frequent visits to different health facilities. This continued as *"I kept going for scans and tests. Every time they said come back after two weeks. It took years to even get one straight answer."* (Rebecca, 41-year-old female). In some cases, participants attributed stressful delays to under-resourced health facilities.

"Hospitals would say they don't have machines, or come next month. It was exhausting just chasing help." (Grace, 37-year-old female)

Expensive medical tests, often in private fertility clinics, were later seen by some participants as money-making ventures. Having to visit the hospital frequently and seeing different doctors was not only expensive but an opportunity for hospitals to do business, as one remarked, *"...saw over ten doctors. Every hospital gave me a new prescription. It was like a business, not care."* (Olivia, 40-year-old female). The general frustrating experience of finding help was summed up by one participant as *"the system is slow. Results take long, appointments are pushed. You wait and wait and get nothing concrete."* (Daniel, 45-year-old male).

Though unknown to the participants then, successive test results seemed to point to specific issues indicative of their fertility problems. For example, *"they checked me and said I was okay. But later they said my sperm count was low. It was frustrating because there was no clear answer."* (Daniel, 45-year-old male) and *"at first they told me everything is okay, then another said it's fibroids, then the next said the fallopian tubes might be blocked. It was always changing."* (Sarah, 37-year-old female). With those experiences, however, participants edged closer to finding a diagnosis. This could be attributed to their persistence in use of problem-focused coping strategies rather than avoidance of fertility care systems. One of our male participants emphatically noted, *"I was committed to have a child. I was ready for anything in good or bad faith [at whatever cost]."* (James, 49-year-old male).

Confirmation of infertility and initial reactions

This subtheme highlights emotional focused coping generally employed by the participants. From the initial hopes and expectations of a normal and quick conception through a long search for help with ongoing inability to have a baby, nothing would have prepared the participants for the news confirming infertility. The distress resulting from receiving the diagnosis reflected the participants' exhausted emotional coping strategies. From immediate heartbreak as *"that moment when the doctor looked at me and said IVF is your only chance... that hit me hard. I broke down."* (Grace, 37-year-old female) to moving from utter numbness to inconsolable acknowledgement of reality as described by this couple in their separate individual interviews.

"When the doctor told me both my tubes were blocked, I didn't know what to say... It felt like the world stopped for a moment. I cried that day. I cried the whole evening when we got back home." (Hannah, 42-year-old female)

“When the doctor told us that both her tubes were blocked, I felt helpless. I didn’t know what to say to her or even to myself. It was painful to see her break down. I wanted to be strong, but even I needed time to process it. Didn’t think we would ever reach a point of needing IVF. It sounded extreme to me at first.” (Daniel, 45-year-old male initially suspected to have low sperm count)

Another male participant reflected on the long journey trying for a baby and finding the cause of infertility.

“...of course we tried but could not get the product. ... so at the end of the day we went for check-up, and we realized that there was blockage somewhere.” (James, 49-year-old male).

For others, the disbelief of a diagnosis of infertility and the proposed solution led them to seek further opinions possibly as they weighed different meaning focused coping strategies. *“I moved to different hospitals... all telling me IVF... I chose IVF because I’d already spent so much money trying all options.”* (Rebecca, 41-year-old female). Throughout the above experiences, individual interactions with social environmental stressors seemed to exacerbate the negative experiences of infertility.

Stigma from family, workplace and community

This theme describes consequences of individual-environmental interactions following expectations of conception starting early in marriage. The two subthemes highlight participants’ ongoing primary appraisals of threatening and/or harmful consequences: insensitive expectations/demands from family and friends; ridiculed and devalued by family and society.

Insensitive expectations/demands from family and friends

Seemingly subtle comments from family members concerned about delayed conception left the participants increasingly alienated from their relatives. Whether actual or perceived, spoken or unspoken, participants appraised and reported finding behaviors of their families and friends emotionally harmful or threatening. The challenge to their values, goals and beliefs increased over time.

“My mum was looking at me as if am not worth it... even my sisters... they end up throwing that tree into your eyes [criticizing] like why don't you give birth to your kids and leave mine alone.” (Grace, 37-year-old female)

“People at the office... everyone else had kids... they used to look at me and ask, why don't you start? After the wedding, now what are you waiting for?” (Sarah, 37-year-old female)

To our participants, such talk was *“...mostly annoying because they did not know what I was struggling with.”* (Sarah, 37-year-old female). Gradually, and perhaps as efforts to emotional regulation were depleted, others felt openly threatened.

Ridiculed and devalued by family and society

In some cases, stigma was more overt, bordering on personal attacks. Both male and female participants reported instances of direct personal ridicule from family and the general community. Insults reported included *“...look at this beautiful woman, she is going to die without kids... she doesn't have a uterus and the man doesn't know....”* (Grace, 37-year-old female). Such statements would have been appraised as threatening and/or harmful by the affected participants. One of the male participants noted, *“In our communities, people talk about IVF. When they hear, they judge, distort the story.”* (Daniel, 45-year-old male). The cumulative effects of experiences of

infertility, challenges with finding help, and how they were perceived by family, friends, and community had serious negative consequences to the participants.

Psychological and emotional effects of infertility

In this theme, we highlight negative outcomes –psychological and emotional –arising from participants’ reduced abilities to cope positively with specific infertility related stressors. Three subthemes all showing poor psychological wellbeing outcomes emerged: Impaired self-identity and self-concept; Social isolation, loneliness and emotional fatigue; and Disappointment, sadness and hopelessness. Experiences of serious psychological distress narrated by the participants can be attributed to several unfavorable and unresolved challenges that characterized individual struggles with infertility. As the realities of infertility unfolded and the hope for normal conception faded with each passing month, the psychological impact on the would be mothers and fathers was evident in unregulated emotions.

Impaired self-identity and self-concept

This subtheme highlights both intrapersonal and interpersonal effects of infertility. The socially constructed ideal for married women to demonstrate the ability to conceive and bear children, was of great concern among female participants. Starting early in their marriages, most of the women reported high expectations for fertility. Inability to conceive after several attempts therefore left many of the participants questioning what had happened to them. The self-concept as a woman, but one who could not have children, seemed unimaginable. Such incongruence resulted in women having a poor sense of self as *“I didn’t want to look at myself in the mirror anymore.”* (Grace, 37-year-old female) and increasingly being confronted with an underlying sentiment *“...that makes you feel like you're less of a woman.”* (Olivia, 40-year-old female).

As feelings of inadequacy among the participants persisted with no end in sight, the women

expressed desperation as their sense of failure became more generalized, possibly due to the absence of a substantive positive meaning focused coping with infertility. Starting with a sense of failure specific to the inability to have a child such as “... *you know you’re working, you’re a woman and I started looking at myself as having failed in that area...*” (Rebecca, 41-year-old female), the participants soon perceived themselves as failures in other important aspects of life. Similar negative meanings were reported in other areas of their lives.

“I felt useless as a wife.” (Sarah, 37-year-old female)

“Nothing was working, I was feeling bad, indeed I was feeling bad, like what is wrong with me, what is stopping me” (Hannah, 42-year-old female)

Due to pre-existing medical conditions for our youngest participant, conception meant much more than just having a child, but a chance to life. Therefore, *“when others got pregnant, I would ask myself what is wrong with me?”* (Amina, 28-year-old female). Poor psychological wellbeing affected interactions with her husband.

“Speaking out became hard for me... I felt like am a failure, so... it’s like I didn’t matter, anything my husband would do that is wrong, I would take it that maybe because I have failed.” (Amina, 28-year-old female)

Negative thoughts and meanings of infertility pushed the affected women into seclusion leaving most of them further away from their immediate family and friends. These thoughts and feelings amidst growing stigma, real or perceived, were either signs of already prevailing mental health problems or increased their risks, as seen in the next subthemes.

Social isolation, loneliness, and emotional fatigue

Social isolation and feelings of loneliness were the other symptoms of poor psychological wellbeing and emotional distress. Participants reported keeping their pains to themselves as *"there was no one I could confide in who would understand."* (Hannah, 42-year-old female) and *"no one knew what I was going through. I couldn't tell even my mother."* (Olivia, 40-year-old female). As the emotional distress intensified with no reliable help, the participants reported deliberately or circumstantially cutting off previously known sources of support including spouses, family and religious gatherings. Their experiences were varied. One participant noted *"I stopped bringing up the issue of having children. We just stopped talking about it."* (Olivia, 40-year-old female). Another reported *"I used to avoid family gatherings. Too many questions."* (Grace, 37-year-old female). For others, *"Friends with kids stopped inviting us to things."* (Amina, 28-year-old female) and *"Even church became hard... the sermons would be about fruitfulness...I let myself from the married people in the fellowship."* (Rebecca, 41-year-old female).

Following such deliberate personal choices amidst perception of being secluded by their social groups, the participants became more vulnerable to risks of severe distress. This later manifested as physical and/or mental health problems.

" started getting ulcers... my self-esteem went down...Even my husband didn't know how much I was hurting... I cried at night by myself... " (Rebecca, 41-year-old female)

"I stopped taking care of myself. I didn't see the point." (Grace, 37-year-old female)

"Everything was eating me down. I would cry alone. I felt darkness everywhere." (Olivia, 40-year-old female).

As the emotional distress intensified, some participants reported a growing distance between them as couples.

“One time he made a statement and said the doctor said you can’t conceive because one of your tubes is blocked... that hurt my feeling because I felt like he was judging me...”

(Olivia, 40-year-old female)

One of the male participants previously suspected to have low sperm count and later his wife’s blocked tubes determined as the cause of their struggles with conception, described the impact of infertility to their psychological wellbeing as *“we were just surviving—not living.”* (Daniel, 45-year-old male). Though somewhat restrained in appraisal, the impact of infertility was felt by both spouses as summarized by another male participant.

“Of course you don’t feel good. It’s kind of frustrating. You get discouraged. You are frustrated. Life can’t go on well.” (James, 49-year-old, male).

For the women who particularly perceived no support from their spouses, the emotional toll of infertility seemed unbearable as *“it was a rollercoaster of different emotions. It became too much... My body was tired, and so was my spirit.”* (Amina, 28-year-old female). However, finding out how infertility impacted their spouses seemed to come as a relief. This perhaps allowed the women to critically think about the emotional toll on their spouses. This was through secondary reappraisal of the effectiveness of couple abilities to cope with infertility. For some participants, new problem focused coping strategies were sought.

“He cried and that’s the day I was like oh... he is going through this... he’s not showing it. So when he talked about that, I understood... we were like what’s the way forward.”

(Olivia, 40-year-old female)

Problem focused coping including support such as *“My husband supported me... we went to the hospitals together... he tried to support as best as he can... I don’t think it was easy for him*

because I was emotionally wrecked." (Sarah, 37-year-old female) seemed to make infertility emotional distress a little bearable. But those who felt unsupported reported severe emotional and psychological threats and harm characterized by sadness, hopelessness and disappointment.

Disappointment, sadness and hopelessness

This subtheme highlights deteriorating psychological wellbeing linked to negative experiences of infertility. Menstrual periods otherwise normal among women of reproductive age, became recurrent and harsh reminders of failure. Whereas missed periods raised hopes, disappointment followed their recurrence.

"I got so excited when I missed my periods, but every time it ended in heartbreak." (Hannah, 42-year-old female)

"I cried every time my period came. It was a reminder of failure." (Olivia, 40-year-old female)

"Each hope made the next disappointment feel worse." (Grace, 37-year-old female).

The cyclical hope and hopelessness with each passing month seemed unbearable to affected participants as *"every time someone said 'it will happen,' it felt more like a lie."* (Sarah, 37-year-old female) and prospects of a childless life became more likely. With hopelessness, some women began to redefine their life goals, an attempt to finding new meaning of infertility.

"There was a time when I was like maybe let me just make my money and I stay without kids..." (Grace, 37-year-old female)

"I was done hoping. I just wanted to try this one last thing." (Olivia, 40-year-old female)

As the participants stopped hoping amidst ongoing inability to have a baby, persistent distress manifested as symptoms of common mental disorders. Anxiety, depressive symptoms and suicidal

thoughts became pronounced as the women became more hopeless amidst growing negativity about self, including fears of marital failure.

“That’s the honest truth, I always hated myself and I always wished for death back then... my journey is full of hate and negativity” (Grace, 37-year-old female)

“There are times when I had suicidal thoughts because I was like why am I living? If I cannot have children, ... maybe my husband is going to leave and find someone else who can actually have kids.” (Sarah, 37-year-old female)

In summary, infertility for the participants was a journey where after unmet expectations of having a baby “you try everything – hospitals, herbs, flashing the tubes – and it keeps failing. You begin to lose yourself” (Rebecca, 41-year-old female) and in the end, “it felt like all doors were closing and IVF was the only one left open.” (Hannah, 42-year-old female). Participants showed growing inability to cope with infertility distress. Interactions with family, friends and community were characterized by repeated primary appraisals of threatening and harmful behaviors and ongoing secondary appraisal of own inabilities to cope. Consequently, symptoms of mental health disorders leading to poor psychological wellbeing were reported by our participants.

Discussion

In this qualitative phenomenological study, we examined experiences of infertility among eight parents, six females and two males, aged below fifty years, who had successfully undergone IVF resulting in at least one live baby within five years prior to the interviews. Results show early normal conception widely expected by participants themselves, their family, and friends. Efforts to find the cause of infertility and care were generally reported as frustrating, leading to delays in diagnosis. Infertility was largely attributed to female factors. The resulting distress from a combination of factors including recurrent failure to conceive for a period ranging between two

to thirteen years; perceived and actual infertility stigma; and challenges in finding a right diagnosis and care increased risks to mental health problems among the participants. We discuss these experiences and the impact on participants in the next sections using the transactional model of stress and coping (23) as a broader lens.

The results of the current study show a sociocultural environment that promotes personal and societal ideals of early conception, especially within marital relationships. Such an environment can have serious negative implications to couples who have planned to delay starting a family, or are struggling with conception for different reasons. We observed the participants' growing distress starting early in their marriages due to personal expectations and societal demands to have a baby similar to findings by Barden-O'Fallon (37) and Walentynowicz-Moryl (38). Whereas the initial perceived delays in conception were explained away by the affected individuals/couples, insensitive and sometimes overt demands from family and friends persisted with serious consequences on their emotional well-being. Such negative reactions are supported by the transactional model of stress and coping (23). The difficulties in emotional regulation which characterized participants' ongoing struggles with conception point to diminishing ability to cope with the stress brought about by apparent realization of failure to meet those expectations. Indeed, several of our participants increasingly perceived themselves as failures due to inability to conceive normally and as fast as earlier anticipated by self and immediate social contacts. This is consistent with previous findings in Uganda where failure was attributed to childlessness (15) and reproductive goals were prioritized (39). The search for help triggered by various personal circumstances added to this initial distress as highlighted in the following paragraphs.

The search for possible underlying causes of infertility was characterized by frustrations attributed to structural gaps in fertility care. There are two possible explanations for the delays in diagnosis, severally reported by the participants. First, the initial expectations of a normal and fast conception as per the socially constructed beliefs and goals in the study setting could have made it harder for the participants to engage appropriate and swift problem-focused coping strategies. We observed initial delays in finding appropriate fertility care due to time spent by participants seeking traditional remedies similar to findings reported by Roomaney and colleagues (18) or general medical care. Structural barriers to accessing ART (40) in the form of delays at diagnosis, complicated the participants' experiences of infertility stress. Such delays are similar to the three delays model used to explain maternal mortality in resource-constrained settings (41). Instead of the participants facing ongoing struggles of conception as possible infertility, many relied on negative emotion-focused strategies including avoidance. Similar negative coping strategies were reported by Asiimwe and colleagues among women seeking fertility care (15).

Upon commencing the search for fertility care, the second explanation for the delays in embracing the diagnosis of infertility is found in the extensions of the transactional theory of stress and coping. Among the three key traits known to influence coping styles is information finding (25). Information seeking helps individuals not only to cope with the diagnosis but also manage treatment choices. Under this trait, however, are people categorized as monitors –those who naturally seek information. Some of the participants in this study could be categorized as high monitors, described as individuals who are less satisfied with the information they receive, appraise the personal threat to be severe and demand more from providers (25). Some of the participants' descriptions of underlying reasons for frustrating efforts to health seeking from one

facility to another, with what they referred to as inconclusive results, reflect the description of high monitors. Even when IVF was suggested by expert care providers as the most viable solution to their infertility, some of the participants continued to seek further professional opinion. A continuous search for alternative options, a phenomenon referred to as mazing (42) was recently reported by Mounce and colleagues (43) in a longitudinal ethnographic study. Unfortunately, the longer they took to receive and/or accept the diagnosis, the more they were exposed to infertility stigma in different social settings, similar to findings by Pratt and others (39). Although infertility stigma is common in sub-Saharan Africa (18, 40), how it manifests as well as its effects equally persist due to personal and societal beliefs.

As personal and societal expectations of a socially construed identity of a woman –one who is able to bear children –intensified, so did the women’s poor self-image and self-doubt. Female participants, especially, found themselves succumbing to their own and societal characterization of infertility as personal failure. Such generalizations of infertility as evidence of personal failure have been attributed to experienced stigma (17). This pervasive label of failure arising from experienced stigma and increasingly internalized by the affected individuals carries serious psychological, behavioral and relational consequences (16, 44, 45). The new negative meaning associated with the stressful experiences of infertility feeds into the emotional dysregulation loop (24), further increasing the affected individual’s sensitivity to social cues of infertility (46). This was evident in how some of the participants described their interactions with family, friends and within religious gatherings. Perceived and anticipated stigma could therefore explain isolation and avoidance behaviors (39) such as cutting off contacts with family and friends as was the case for some of the participants. The stress associated with isolation and avoidance could further compromise the affected individual’s wellbeing (27). The resulting cause

and/or effect relationship with psychopathological symptomatology is discussed in the following section.

The cumulative lack of control and helplessness associated with infertility stemming from unmet expectations of a normal and fast conception exposed the participants to serious emotional and psychological challenges. Prolonged efforts to seek help exacerbated participants' distress due to failing emotion-focused coping. The current findings highlight specific issues linking experiences of infertility to psychological distress (47). Key among these are unmet personal and social expectations, delays in diagnosis and infertility stigma. Delays in diagnosis of infertility and finding appropriate solutions for example meant that the participants experienced involuntary infertility as a reproductive condition with serious negative psychological implications. Social withdraw and isolation because of infertility stigma and deteriorating mental health of the participants made the affected individuals prone to serious emotional distress. As seen among our participants, women experiencing infertility face more severe psychological distress including anxiety, depression than their male counterparts (47). It is however important to note that our sample had a very small number of male participants who also did not report male factor related infertility. This could explain the less severe distress they reported compared to the female participants. Additionally, structural stigma from cultural or religious beliefs that portray infertility as arising from curses and those affected as responsible/guilty (17) could have led to specific psychopathological experiences such as sadness, hopelessness and suicidal ideations.

Psychological distress associated with specific negative experiences of infertility was widely reported indicating increased risks to serious mental health challenges for the affected individuals/couples. Female participants who generally perceived themselves as failures reported

severe depressive symptoms including guilt and suicidal ideations. This is consistent with findings by Khalesi and colleagues (47) who reported severe distress among women. However, our findings from a highly distressed self-selected sample may not be transferrable and should therefore be interpreted with caution.

A non-supportive social environment of family, friends and workmates who demonstrated growing infertility stigma further compromised the affected individuals' ability to cope with infertility stress. Consequently, symptoms characteristic of depression, anxiety and stress generally reported by the participants are similar to results of recent studies in Uganda (48), Africa (17, 18) and elsewhere (27, 49-51). Despite a small number of men in this study, the evaluation of the impact of infertility on their wellbeing add to results from a recent study comparing anxiety, depression and stress among men and women (47). Psychological issues such as isolation, self-blame and poor self-image reported mainly by female participants have also been reported among men facing infertility (49). These findings are also consistent with a recent quantitative study showing that emotional focused coping, manifesting in our sample as internalized failure, is linked to higher infertility stress (27).

Important to note, self-neglectful behaviors and suicidal ideas reported by some of our participants followed prolonged and serious negative experiences of infertility. Besides being childless and having depressive symptoms, non-positive reappraisal highlighted in the transactional model of stress and coping has been reported to predict suicidal risks (52). Although suicidal ideation reported by some participants in our sample of self-selected highly distressed sample should be interpreted with caution, suicidal ideation resulting from infertility has been reported by women pursuing fertility treatment (53). Participants of the current study rarely reported positive reappraisals of their experiences of infertility, an unambiguous indicator

of the emotional toll persistent negative experiences had on their well-being (15, 53). Left untreated, these psychological effects of infertility may further diminish the affected individuals' chances of conception. The IVF parents in this study, as well as their children, may face long-term risks to quality of life, social and emotional outcomes associated with their negative perinatal experiences. Some of the participants still expressed distress during our interviews, a few years after delivery, following IVF. Future quantitative validation or large mixed methods within Uganda and similar contexts could further our understanding of the rich narratives reported by our participants.

We also noted that none of the IVF parents reported receiving any formal psychosocial support during their extended period of infertility. Moreover, age, high educational level and access to resources by our sample did not seem to buffer the effects of distress associated with infertility contrary to recent results (50). However, male participants though distressed themselves, played a more supportive role to their spouses who reported direct effects of infertility. For the current study sample, infertility was generally attributed to female factors except for one female participant. Male participants actively demonstrated support for their distressed spouses facing infertility (16). Some female participants including one whose spouse was later diagnosed with oligospermia seemed surprised that their spouses were also emotionally affected by infertility. Pinzon and Rotoli (54) similarly reported an underestimation of the emotional impact of infertility in men compared to women. Negative masculinity beliefs that may portray men as strong and not needing emotional support could be responsible for these contrasting experiences. A recent review on the psychological impact of male infertility noted that many men report feelings of emotional suppression (55). The emotionally affected men would therefore remain both unexpressive of their underlying negative emotions and without any

help. Increased risks to severe mental health problems would therefore be the likely outcome for such men. Due to a small number of male participants, we could not make further meaningful comparisons of the psychological implications of infertility by gender. This can be an area of interest in future studies.

Study Limitations

Whereas our findings illuminate intense experiences among those who persisted to IVF success, they are not representative of all infertile individuals or couples in Uganda. Specifically, the current findings do not reflect the experiences of infertility among the majority in rural and resource limited areas of the country and those who have neither sought nor been successful with IVF. However, our detailed findings can trigger further examination of infertility and its impact across diverse populations.

A small number of participants who took part in this study, largely attributed to infertility stigma, could have limited the diversity of experiences reported. Moreover, due to a small sample and absence of participants from low social economic populations, it was impossible to make any meaningful comparisons. Though we approached and invited several potential participants, a number of men opted out after showing interest in the study without any reason. But the individuals who upon learning the purpose of the study voluntarily accepted to be interviewed, their experiences reported in this study, are informative about the issues pertaining infertility in the study area.

Lastly, a male research interviewer for a study involving majority women may have influenced the findings we obtained. On one hand female participants' responses seemed to take on a more educative perspective perhaps on assumption that the interviewer had very little prior understanding of women's experiences of infertility. On the other hand, male participants might

have opened up less about their experiences for fear of judgement as might be expected in cultures that do not expect men to be expressive about their emotional challenges. Consequently, we might have gained more information from female participants and less from males.

Conclusion

Societal and individual expectations of normal and fast conception at the inception of marriage despite a growing prevalence of infertility heighten risks of stigma –real, perceived or anticipated –among couples wishing to start families but facing delays. The stress that comes with delays in conception drive affected individuals into a search for possible causes and remedies from traditional cultural sources and medical health facilities. However, ineffective traditional remedies as well as inconclusive medical tests prolong the diagnosis. A sociocultural environment that espouses traditional cultural beliefs and expectations about normality of conception increases risks of distress. Limited social support is available for individuals experiencing struggles with conception and those seeking help. Moreover, because of inaccessible specialized fertility care and absence of screening for associated mental health challenges, serious psychological and emotional problems are witnessed among individuals experiencing infertility in Uganda.

Practical Implications

Integration of fertility and mental health care in primary maternal health packages to support couples suspecting and/or experiencing infertility is urgently needed. This can reduce the challenges couples face while seeking fertility care and mitigate the psychological and emotional impact of diverse forms of stigma as well as alleviate the sense of failure suffered by especially women. Such integrated packages should also streamline referral systems involving established specialized fertility facilities and reduce the delays in finding appropriate help. Mental health

practitioners such as clinical psychologists and counselors with fertility specific psychosocial interventions are urgently needed to support this growing population.

Public health sensitization campaigns on the growing prevalence of infertility, negative cultural beliefs about infertility and the impact of those beliefs on affected individuals can help reshape community attitudes, enhance public understanding and foster social support. Such campaigns can be conducted by multidisciplinary team of experts on infertility working collaboratively with empowered individuals with lived experiences.

Broader studies (rural, male-focused, unsuccessful cases, quantitative validation) are urgently required in Uganda. Quantitative validation and large mixed methods studies for example can complement the growing rich narratives about experiences of infertility and associated psychological problems. Findings from such studies would inform policy on fertility care in Uganda as well as the nature and feasibility of appropriate interventions to support the affected individuals and couples.

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Author Contributions

S.O: Conceptualized the study, supervised the study, analyzed data, wrote the main manuscript text, reviewed the manuscript and approved submission.

B.A: verified the analysis, reviewed the manuscript and approved submission.

M.M.B: verified the analysis, reviewed the manuscript and approved submission.

A.I.M: conceptualized the study, recruited participants, conducted the interviews, analyzed data, reviewed the manuscript and approved submission.

All authors have agreed to be personally accountable for their own contributions and to ensure that questions related to the accuracy or integrity of any part of the work, even ones in which the author was not personally involved, are appropriately investigated, resolved, and the resolution documented in the literature.

Declarations

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Human Ethics and Consent to Participate.

Human ethics were observed in accordance to the Uganda National Council for Science and Technology (UNCST) and adhered to the Helsinki Declaration, as reviewed and approved by TASO IRB. All participants gave verbal and informed written consent at the point of recruitment and prior to interviews respectively.

Consent for Publication: Not applicable

Availability of Data and Materials

Data supporting this work is available at Mendeley Data, V1, doi: 10.17632/t6n3sgt7fn.1

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