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## Defining infertility-related distress: identifying clinical targets for psychotherapy

Loveness Dube<sup>1</sup>, PhD,  
Nokuthula Nkosi-Mafutha<sup>2</sup>, PhD,  
Ashley A. Balsom<sup>1</sup>, M.A.,  
Jennifer L. Gordon<sup>1</sup>, PhD\*

### Authors' Affiliation:

<sup>1</sup>Department of Psychology, University of Regina, Regina, Saskatchewan, Canada.

<sup>2</sup>Department of Nursing Education, University of the Witwatersrand, Johannesburg, South Africa

**ORCID IDs:** Loveness Dube: 0000-0002-0446-0608; Nokuthula Nkosi-Mafutha: 0000-0002-3227-1775; Ashley Balsom: 0000-0002-1795-8093; Jennifer Gordon: 000-0001-6401-6827

**\*Corresponding author at:** Department of Psychology, University of Regina, 3737 Wascana Pkwy, Regina, SK S4S 0A2, Regina, Saskatchewan, Canada. Email:

[jennifer.gordon@uregina.ca](mailto:jennifer.gordon@uregina.ca)

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## Abstract

**Objectives:** An estimated 30-40% of women attending infertility tertiary care facilities experience clinically significant depression and anxiety. However, current psychological interventions for infertility are only modestly effective in this population. In this study, we aimed to identify the specific psychological components of infertility-related distress to assist in the development of a more targeted and effective therapeutic intervention.

**Design:** A qualitative approach using semi-structured interviews and focus groups with women who have experience with infertility and also mental health professions specializing in the field of infertility.

**Participants:** Twenty-one women (aged 25-41 years) struggling to conceive for  $\geq 12$  months and 14 mental health professionals underwent semi-structured interviews about the psychological challenges related to infertility.

**Results:** Five themes, each divided into subthemes, emerged from the data and these were developed into a model of infertility-related distress. These five themes are: (1) Anxiety, (2) Mood disturbance, (3) Threat to self-esteem, identity and purpose, (4) Deterioration of the couple, and (5) Weakened support network.

**Conclusions:** The results of this study suggest specific clinical targets that future interventions treating infertility-related distress should address.

**Key words:** Mental health; Qualitative research; Reproductive medicine

### Strengths and limitations of this study

- The study adopted a patient-oriented approach and included interviews with mental health professionals specializing in infertility.
- The qualitative approach provided an in-depth socio-contextual and detailed description and interpretation of the experiences of the infertile women.
- All participants were in heterosexual relationships, perhaps preventing the discovery of themes specific to same-sex couples.

## INTRODUCTION

Globally, 15% of couples are affected by infertility (1, 2), typically defined by the failure to achieve a clinical pregnancy after 12 months or more of regular unprotected sexual intercourse (3). While male and female factor infertility are roughly equivalent in prevalence (4), it is well documented that women generally bear the brunt of infertility-related burden, both physically and mentally, regardless of the cause (5, 6). In fact, research suggests that an estimated 30-40% of women attending infertility tertiary care facilities experience clinically significant depression and anxiety (7-10) and the rates are equally high in non-treatment seeking women (11). At least half of infertile women have described infertility as the most upsetting event of their lives and their distress has been found to be comparable to that of people with other chronic diseases like cancer (12). Infertile women also reported feelings of shame, self-blame, grief, loss, anger, sadness, and lack of femininity (13, 14).

Despite the high rates of distress in this population, one meta-analysis suggests that current psychological interventions – most of which are merely modified versions of existing therapeutic approaches targeting general depression and anxiety – are only modestly effective in this population (15). Though they were found to result in small reductions in anxiety, they were not found to improve depressive symptoms, infertility distress or marital functioning when adjusting for publication bias. Furthermore, the overall effect size associated with randomized controlled trials of psychological interventions on combined psychological outcomes was non-significant and efficacy was not found to differ according to intervention type. There is therefore a great need to develop a new psychological intervention that is more effective in reducing infertility-related distress. We propose to do so by starting with a careful look at the specific clinical targets that an infertility-specific intervention should address. The purpose of the current

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2  
3 study was, therefore, to identify the unique psychological challenges faced by women struggling  
4 with infertility and to suggest other components of psychological therapies that have not been  
5 used in the treatment of infertility-related distress. The goal was achieved by interviewing both  
6 women themselves and mental health professionals that specialize in treating this population. An  
7 inductive approach was then taken to identify the major themes and sub-themes characterizing  
8 infertility-related distress.  
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## 16 **METHODS**

### 17 **Study design**

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20 This study employed a qualitative approach using semi-structured interviews to explore the  
21 experiences of women and mental health professionals. The qualitative approach, was chosen  
22 with the aim of providing in-depth socio-contextual, detailed description and interpretation of the  
23 psychological challenges faced by infertile women (16).  
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### 33 **Patient and public involvement**

34  
35 A panel of six women who were not study participants and who have experience with infertility  
36 collaborated with the researchers at two stages in this research. First, at the development of  
37 semi-structured interview guides and second, during the final stages of data analysis in the  
38 naming of the themes and sub-themes.  
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### 45 **Participants and sampling**

46  
47 The target population included 1) women who were experiencing either primary or secondary  
48 infertility and 2) mental health professionals specializing in the field of infertility. Purposive and  
49 snowball sampling strategies were used to recruit both women and mental health professionals  
50 (17). To recruit women, flyers were posted in a local fertility clinic and an advertisement was  
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3 posted on the Facebook page of a local infertility support group. Eligible participants were 18  
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5 years or older and had personal experience with infertility.  
6  
7

8 Eligible mental health professionals included master's and PhD-level Clinical  
9  
10 Psychologists, Counseling Psychologists, and Social Workers throughout Canada and the U.S.  
11  
12 who had a self-reported specialization in infertility. Eligible mental health professionals were  
13  
14 identified via a broad internet search of clinicians affiliated with or endorsed by an infertility  
15  
16 clinic, and clinicians in private practice advertising a specialization in infertility. Those identified  
17  
18 through the search were invited via email to participate.  
19  
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22

23 This study was conducted between November 2019 and February 2020 and approved by  
24  
25 the Research Ethics Board of the University of Regina (REB# 2019-137). All women with  
26  
27 infertility provided written consent and received a \$10 gift card. Mental health professionals  
28  
29 provided oral consent over the phone and did not receive compensation. All participants gave  
30  
31 consent to be audio recorded.  
32  
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34

### 35 **Setting**

36  
37  
38 Face to face interviews and focus group discussions were conducted at the research site at the  
39  
40 University of Regina. Other interviews were conducted over the phone.  
41  
42

### 43 **Data collection**

44  
45  
46 Data was collected using two semi-structured interview guides (one for women and one for  
47  
48 mental health professionals). The first interviews were pilot tests in order to refine the interview  
49  
50 guides and the data was included in the analysis. Table 1 shows an example of questions  
51  
52 included in both interview guides. Demographic information was collected via an online survey  
53  
54 in Qualtrics (Qualtrics Inc., 2019) (18) for women with infertility and at the start of the phone  
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1  
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3 interview for mental health professionals. Focus group discussions for women participants were  
4  
5 chosen as a preferred method of data collection as they encourage participants to explore topics  
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7 that are seldom discussed (19), though the option of an individual interview was provided for  
8  
9 those preferring to maintain privacy. Telephone interviews were conducted only when face to  
10  
11 face interviews were not logistically possible. All mental health professional interviews were  
12  
13 conducted by phone. Data for both women and mental health professionals was collected until  
14  
15 saturation was achieved (i.e. new information was no longer generated). Member checking was  
16  
17 achieved by paraphrasing and summarizing the participant's contributions during focus groups  
18  
19 and interviews. The researchers took field notes, and all interviews were audio recorded and  
20  
21 transcribed for content analysis.  
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27 **Table 1.** Example questions from the semi-structured interview guides  
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29

30 <b>Women with Infertility</b>
31
32 What are the daily emotional challenges that you face as you have struggled to conceive?
33
34 Throughout the whole process, when have things been the hardest for you?
35
36
37 What have your interactions with the medical community been like throughout your fertility
38
39 struggles?
40
41
42 What have your interactions with your family and friends been like throughout your fertility
43
44 struggles?
45
46 <b>Mental health professionals</b>
47
48 In your experience, what are the most common/specific challenges or symptoms that women
49
50 present with and seek help for?
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## Data analysis

We followed the Consolidated criteria for reporting qualitative studies (COREQ) to comprehensively report on important features of a qualitative study (20). Preliminary data analysis was concurrent with data collection and was conducted by LD. The main data analysis was conducted by two independent authors, LD and NNM. JLG acted as an auditor of the data. Disagreements in the analysis process were discussed and resolved by consensus. An inductive approach to content analysis was used to identify patterns in the qualitative data and was conducted in 4 phases including initialization (reading transcriptions and highlighting meaning units, coding and looking for abstractions in participants' accounts, writing reflective notes, classifying and comparing), construction (labelling, translating & transliterating, defining and describing, immersion and distancing), rectifying (relating themes to established knowledge, stabilizing), and finalization (developing the storyline) (16). Final decisions about the naming of themes and subthemes were made in collaboration with the panel of women who had helped prepare the interview guides, mentioned above. NVivo (NVivo 12) software was used to facilitate data management, coding and analysis (QSR International Pty Ltd., 2019) (21).

## RESULTS

Thirty-three women responded and met eligibility criteria. Data saturation was achieved after the 21<sup>st</sup> interview and data collection was stopped. Two focus groups of 4 participants each, 7 individual face-to-face interviews, and 6 individual telephone interviews were conducted. Table 2 shows the demographic characteristics of the women participants.

**Table 2.** Demographic characteristics of women participants

	Frequency	% or Mean (SD)
<b>Age (years)</b>		
25-30	4	19
31-35	7	33
36-40	6	28
>41	2	10
Not reported	2	10
<b>Education</b>		
University degree	15	71
High School Diploma	5	24
Not reported	1	5
<b>Marital status</b>		
Married	17	81
Single but cohabiting	2	10
Single/never married	1	5
Not reported	1	5
<b>Combined household income (CAD)</b>		
113 000 and greater	16	76
90 -112 999	2	9
70 – 89 999	1	5
35 – 49 999	1	5
Not reported	1	5
<b>Ethnicity</b>		
Caucasian	21	100
<b>Pregnancies carried full-term</b>		
0	11	52
1	6	28
2	2	10
3	1	5
Not reported	1	5
<b>Currently trying to conceive</b>		
Yes	12	57
No	9	43
<b>Current time trying (mean, SD)</b>		
Months	23.83	23.8 (22.1)
<b>Have pursued fertility treatments</b>		
Yes	18	86
No	3	14

One hundred and twenty-one mental health professionals were contacted and 16 responded.

Fourteen consented to participate in the study and completed the telephone interview. Eight

1  
2  
3 mental health professionals were registered psychologists (4 PhD and 4 Masters), 3 were  
4  
5 registered psychotherapists (1 PhD and 2 Masters), and 3 were registered social workers  
6  
7 (Masters). All mental health professionals were women and most practitioners worked in private  
8  
9 practice with years of experience ranging from 2 years to 30 years. The length of each interview  
10  
11 ranged from 30 minutes to 100 minutes, with an average of 60 minutes.  
12  
13  
14

15 Findings from this study illuminated five important themes which were developed into a  
16  
17 model of infertility-related distress. These five themes are: (1) Anxiety, (2) Mood disturbance,  
18  
19 (3) Threat to self-esteem, identity and purpose, (4) Deterioration of the couple, and (5)  
20  
21 Weakened support network (Table 3). In the following section, themes will be discussed in  
22  
23 detail, with supporting quotations provided from different participants: Individual Interview (II),  
24  
25 Focus Group (FG) and Mental Health Professional (MHP).  
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### 30 **1. Anxiety**

31  
32 Anxiety was perhaps the most highly endorsed aspect of infertility-related distress. Both the  
33  
34 mental health professionals and women interviewed described relentless anxiety manifesting  
35  
36 itself through multiple behaviors, described below, aimed at seeking reassurance and avoiding  
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38 further distress.  
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**Table 3.** Identified themes and sub-themes of infertility-related distress.

<b>Theme</b>	<b>Sub-theme</b>
<b>Anxiety</b>	Anxious rumination Avoidance of fertility reminders Narrowed focus on infertility-related activities. Excessive information seeking
<b>Mood Disturbance</b>	Emotional lability Helplessness Emotional exhaustion
<b>Threat to Self-Esteem, Identity and Purpose</b>	Unmet expectations for self and one's future Self-blame Shame
<b>Deterioration of the Couple</b>	Partner differences in coping Negative impact on couple's sex life Stress related to financial burden of fertility treatments Couple disagreements on next steps
<b>Weakened Support Network</b>	Strained relationships with friends and family Social stigma Social isolation Feeling dismissed by healthcare providers

**1.1. Anxious rumination.** Women with infertility reported anxiously thinking about their infertility, often to the point of “obsession”. Both the women and mental health professionals described incessant thoughts about the causes and treatment of their infertility and monitoring of their menstrual cycle and symptoms that might indicate pregnancy, to be all-consuming. One woman reflected: “I was developing a lot of anxiety and spending so much time hovering about

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2  
3 this like it was just becoming completely all consuming”. (FG). One mental health professional  
4 considered anxiety to be the most prominent feature of infertility-related distress:  
5  
6

7  
8 One of the primary emotional symptoms is anxiety... rumination over the uncertainty,  
9 and anxiety sometimes about the medical procedures, anxiety related to going to the  
10 fertility clinic... Anxiety related to just not knowing (MHP).  
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16 **1.2 Avoidance of fertility reminders.** Many women reported feeling the need to avoid  
17 activities and social events that would expose them to reminders of others’ fertility, such as  
18 family gatherings where pregnant women, children, and babies would be present. Women also  
19 described avoiding social media to avoid seeing pregnancy and birth announcements:  
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22

23  
24 And then all of a sudden, birth announcements... pregnancy announcements start to  
25 bother you... you don't want to go on your social media because you just don't want to  
26 see everybody having fun with their babies and their families and getting pregnant... and  
27 you just feel like you're left behind. (II)  
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34 Mental health professionals also reported frequently observing this avoidance:  
35  
36 “Everything and everyone can be very triggering” said one. Both women and mental health  
37 professionals linked this avoidance of potentially triggering social situations with a gradual  
38 increase in social isolation and distancing from once-close friends and family members.  
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44 **1.3. Narrowed focus on fertility related activities.** This sub-theme was primarily  
45 endorsed by mental health professionals who observed that, over time, women would  
46 increasingly focus on their attempts to conceive at the cost of their previously enjoyed activities.  
47 Events and plans would be put on hold for the sake of their treatments or ‘in case’ they became  
48 pregnant. Mental health professionals also explained that, over time, getting pregnant often  
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3 becomes the topic of every conversation within a couple and all actions and activities are solely  
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5 focused on conceiving and the next steps in the process:  
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8 Fertility treatment becomes everything, it consumes their everyday life...a tendency for  
9  
10 couples going through fertility [treatments] or struggling with infertility is that that's all  
11  
12 they talk about fertility and next steps. (MHP)  
13  
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16 Relatedly, one woman explained that the scheduling of fertility treatments often makes it  
17  
18 difficult to plan:  
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21 I hate that I can't plan stuff because we are still doing IVF, we have embryos that are  
22  
23 still on ice. And so, every try is three months apart and we love to travel but it's like you  
24  
25 can't book because you don't know when exactly that next treatment is.... It's just that  
26  
27 lack of being able to plan (FG)  
28  
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31 **1.4. Excessive information seeking.** Spending an excessive amount of time seeking  
32  
33 information about the causes and potential treatment of infertility, usually via the internet, was  
34  
35 endorsed by both women and mental health professionals: "Sometimes I do see... pure  
36  
37 obsession, it can actually look like where the person is frantically researching online repeatedly  
38  
39 for explanation as to why they haven't gotten pregnant." (MHP). Mental health professionals also  
40  
41 voiced concerns that this constant searching for answers was potentially harmful for women as  
42  
43 the information they obtained was often of questionable validity.  
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48 **1.5. Summary.** Every woman and health professional interviewed endorsed elements of  
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50 anxiety related to infertility. Women who had experience with fertility treatments related their  
51  
52 anxious rumination to the success of the many procedures involved in the treatment process  
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54 while women who had only struggled to conceive without medical intervention reported being  
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3 very focused on the different phases of their menstrual cycle, identifying signs of fertility, and  
4 looking for signs that a cycle was positive. This excessive mental energy devoted to all things  
5 infertility, coupled with a desire to avoid witnessing evidence that others are conceiving without  
6 difficulty, results in a decrease in engagement of previously enjoyed activities and social  
7 withdrawal.  
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## 14 15 **2. Mood disturbance**

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18 This theme captured women's experience of enormous fluctuations between positive and  
19 negative emotion, eventually leading to complete exhaustion and, in some cases, depression.  
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23  
24 **2.1. Emotional lability.** Perhaps as common as the endorsement of anxiety was the  
25 description of infertility as an "emotional rollercoaster": at the start of each cycle, hope and  
26 excitement would build, only to be met with extreme disappointment and grief following each  
27 negative test or miscarriage:  
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32  
33 Every month, you go through this cycle of excitement or hope and then followed by no  
34 success... you get depressed, you get very discouraged or very down...and then you  
35 think, 'Oh, I'm not going to invest any more energy', but then just by nature, you do. And  
36 then you get hopeful and excited again, and you just go through this rollercoaster of  
37 emotions that way (II)  
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45 Women who had undergone fertility treatments explained that their mood was highly  
46 dependent on the outcomes of each step in fertility treatments: ultrasounds, egg retrieval, and  
47 embryo transfer. Some women also reported that the hormones taken for infertility exacerbated  
48 their emotional lability: "The hormones that they have you on wreak havoc with my entire being,  
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3 I felt crazy.” (FG2). Other women reported being overly sensitive or irritable in their daily lives  
4  
5 because of their high stress levels, directly related to their struggles to conceive.  
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8  
9 **2.2. Helplessness.** Several women stated that one of the biggest challenges related to  
10 infertility was the feeling of being completely helpless in the process of trying to conceive.  
11  
12 Women reported feeling extremely frustrated by their lack of control over the outcome of any  
13 given cycle. One woman participating in a focus group lamented: “One of the hardest aspects is  
14 the helplessness that I feel...because most of the things in my life - it's like ok you do A B C D  
15 and you get this outcome but with this there's just no guarantees.”  
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23 One participant explained that the sense of a lack of control over the process led her to  
24 even contemplate not taking her medication so that she could at least have “some sense of  
25 control over [her] destiny”. Women also expressed frustration at the lack of information and  
26 choice with regards to their treatment options: “I feel like they have a very set order [in fertility  
27 clinics but] they are not going to tell you why this is the order in which they do things” (FG).  
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29 Mental health professionals similarly remarked that women are given little opportunity to  
30 determine the course of their treatment in medical settings.  
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40 **2.3. Emotional exhaustion.** Participants reported that the constant alternation between  
41 hope and despair, along with their feelings of helplessness, led them to become emotionally  
42 drained. One woman explained that fertility treatments had drained her to the point of requiring a  
43 mental health break from work: “I went to the doctor and I said to her, ‘I need to get off work, I  
44 need to be on stress leave because I can't do this anymore.’” (II). Another woman recalled a time  
45 when she had “hit rock bottom” and became suicidal because of her difficulties conceiving.  
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3 **2.4. Summary.** Nearly all women reported that their mood dipped at certain points  
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5 throughout their cycle each month, particularly after a negative outcome. Feelings of complete  
6  
7 helplessness over the process and outcome of each cycle was also very highly endorsed. A  
8  
9 smaller subset of women, however, related the constant up and down from hope to despair to the  
10  
11 development of emotional exhaustion and what sounds like clinical depression.  
12  
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### 14 15 **3. Threat to self esteem, identity and purpose**

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18 This subtheme captured women's reports that infertility had contributed to a questioning of their  
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20 identity and negative internal dialogue about their worth and the worth of their life in the absence  
21  
22 of motherhood.  
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26 **3.1. Unmet expectations for self and one's future.** Many of the women reported an  
27  
28 enormous sense of loss as they reflected on their childhood dreams of being a mother. One  
29  
30 woman remembered:  
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33 When I was a kid, I wasn't dreaming about being a doctor or vet or thinking about the  
34  
35 perfect wedding, I was thinking about being a mom. And it was just a sense that the  
36  
37 vision of what I had for my future wasn't possible. (FG)  
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40  
41 Mental health professionals added that for many women, motherhood is so closely tied to  
42  
43 their identity as a woman that diagnosis threatens their very sense of who they are as a person:  
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46 The number one thing that I see and can identify hands down is there is an attack on their  
47  
48 identity and their sense of self, the narrative that they believed about who they were, what  
49  
50 their reproductive story was, and they feel very shattered from that because this story is  
51  
52 not playing out. (MHP)  
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3 Mental health professionals also reported that women having to pursue third-party  
4 reproduction also grieve: the loss of pregnancy in the case of surrogacy, and the loss of genetic  
5 connection to their child in the case of egg donation.  
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11 **3.2. Self-blame.** Several women reported believing that they were partly to blame for  
12 their infertility, particularly among women with female factor infertility: “You have to deal with  
13 the mental aspect of knowing...that I was the reason that we didn’t have kids... If [my husband]  
14 was with someone else, he could be having those kids.” (II). Women also reported that they  
15 tended to question whether any of their behaviors might be contributing to their diagnosis or a  
16 failed cycle. One woman, a long-distance runner, recalled: “A few of my IUIs were right after  
17 doing a very long race and so I felt like maybe that’s why it didn’t work. I was blaming myself  
18 that it didn’t work.” (FG). Mental health professionals corroborated these reports.  
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31 **3.3. Shame.** Many women reported feeling ashamed of their diagnosis of infertility,  
32 seeing themselves as “broken”, leading them to keep their struggles a secret or to share with only  
33 a few close others: “If I had cancer, it would have been open, and we could have talked about it  
34 and my community would have supported me. But when it's infertility, you feel different,  
35 isolated, and embarrassed, and ashamed.” (II). Mental health professionals echoed the same  
36 sentiment, highlighting the difference between how infertility is perceived compared to other  
37 medical conditions.  
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48 **3.4. Summary.** Within this theme, we see that infertility often triggers an existential  
49 crisis of sorts: a profound questioning of what it means to be a woman in the absence of fertility  
50 and the potential for motherhood. Women are left wondering what their lives will look like and  
51 what value it might have if motherhood is never achieved. This seems to be particularly the case  
52 for women who report having wanted to be a mother since childhood.  
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#### 4. Deterioration of the couple

As one mental health professional reported, some relationships are strengthened by the process of struggling to conceive while others suffer to the point of divorce. The following challenges, however, appeared to be common even among couples whose relationship was strengthened overall.

**4.1. Partner differences in coping.** Women described their frustration related to differences in coping between themselves and their partners, often such that women took a more active role and expressed their emotions more openly than their partners, leading them to perceive their partners as being less emotionally invested in the goal of conceiving:

It makes me feel like I'm the one that's always worrying and stressing and thinking about things and making appointments and tracking my cycle and kind of carrying the burden in a way...he's just kind of very laid-back about the situation...it gets a little frustrating for me. (II)

Another woman reflected on her and her husband's different ways of coping with grief following a miscarriage:

The first time the miscarriage happened, my husband kind of grieved separately because he didn't want to grieve in front of me because he thought that it wouldn't help how I was doing with it...so I just thought like, "Hey, we had a miscarriage, and he's fine." (II)

Mental health professionals agreed that many challenges within the couple relate to partners not 'processing' events surrounding infertility at the same pace.

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3 **4.2. Negative impact on couple's sex life.** A deterioration of the couple's sex life was  
4 commonly endorsed as participants reported that, over time, the purpose of sex became solely to  
5 conceive rather than intimacy or enjoyment: "it just seems like work" (II). One mental health  
6 professional described sex as becoming "transactional" in nature and reported that women often  
7 found it difficult to engage without thinking about the goal of conceiving.  
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15 **4.3. Stress related to financial burden of fertility treatments.** Given the high costs of  
16 fertility treatments, for the most part not covered by medical insurance, women reported that  
17 strained finances became a prominent topic of conversation among couples pursuing assisted  
18 reproductive technologies:  
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25 Conversations around the cost of everything just because that puts a lot of strain on our  
26 relationship...how can we afford it...how can we make it work. We don't really have  
27 time to wait and save up for this, we just have to figure it out now. (FG).  
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33 Concerns about finances would also lead to stressful discussions surrounding the  
34 feasibility of continuing treatment. The same sentiment was echoed by mental health  
35 professionals who described the financial strain brought on by fertility treatments as being a  
36 challenge for most couples.  
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43 **4.4. Couple disagreements on next steps.** A few women reported that tension within  
44 the couple arose due to differences in opinion about next steps to take in trying to conceive: "I  
45 got divorced because... I think he was done before I was, he just didn't want to do it anymore."  
46 (FG). One woman recalled that she and her husband went into a doctor's appointment with very  
47 different intentions and expectations, which led to conflict afterwards: "I went in thinking like,  
48 'hey, we're going to get the information and move forward,' he went in thinking, 'okay, I'm  
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3 going in to get the information and then make a decision on that.’ So, we were on different pages  
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5 going in.” (II).  
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8 **4.5. Summary.** While a few women reported that their relationships were strengthened  
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10 overall because of going through the challenges of infertility together, all women endorsed some  
11  
12 difficulties within the couple at one time or another. A subset of women reported that their  
13  
14 relationship had been severely tested (or severed) by their struggles with infertility and these  
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16 serious conflicts seemed to be primarily related to differences in opinion regarding next steps to  
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18 take regarding treatment.  
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## 23 **5. Weakened Social Support Network**

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25 The theme of weakened social support networks highlighted participants’ struggles with their  
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27 loved ones due to stigma and lack of education surrounding infertility. Women also reported that  
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29 their experiences were often dismissed by health service providers.  
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33 **5.1. Strained relationships with friends and family.** Women explained that  
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35 relationships with friends and family were often strained in the context of infertility, in part due  
36  
37 to the barrage of unhelpful comments and questions they received from well-meaning loves ones.  
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39 One woman explained why she felt that she couldn’t open up to her friends about her infertility:  
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43 I have a lot of friends who mean well, and they just keep saying it’ll happen...I just don’t  
44  
45 know what they want me to say to that... I feel like if I talk to them about it, they’re just  
46  
47 gonna be like ‘oh just stay positive’. (FG)  
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51 Several women reported that their family members often showed a lack of understanding  
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53 about the emotional pain they were experiencing, even when they were open with them about the  
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55 challenges they were facing: “All my mom said was that I was a b\*\*\*\*\* that Christmas. And so,  
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3 there was just no understanding.” (FG). Participants also struggled with feelings of envy,  
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5 jealousy, and resentment towards friends or family who had conceived easily, which also  
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7 contributed to distance with once-close loved ones:  
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11 The relationship with my brother is still pretty strained. Him and his wife actually ended  
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13 up getting pregnant five weeks before I did, and they only tried for a couple of days...  
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15 and then got pregnant right away. ...I felt like they didn't deserve their pregnancy  
16  
17 because they didn't have to work for it. (II).  
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21 **5.2. Social stigma.** Women also reported that they perceived a great amount of social  
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23 stigma related to infertility, which created anxiety around discussing it openly: “I felt reluctant to  
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25 tell friends and other people. And I still haven't told everyone in my life...just because I didn't  
26  
27 want to be an object of pity, I didn't want anyone to think I was a barren woman.” (II). Other  
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29 women abstained from telling others about their infertility because they did not want to be  
30  
31 judged by friends and family who might comment on the woman's potential role in contributing  
32  
33 to her problems conceiving.  
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37 **5.3. Social isolation.** An increase in social isolation seemed to be a consequence of  
38  
39 several processes – women's avoidance of fertility reminders (from theme 1), their attempts to  
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41 avoid unhelpful comments and questions from others, and the pressure to hide their  
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43 preoccupation with their infertility: “I feel like it kind of closed off some of my opportunities for  
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45 healthy, normal socialization...and I think to some extent, that's impeded my ability to form  
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47 closer relationships with people too.” (II). For example, one participant recounted avoiding get-  
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49 togethers at bars or pubs in order to avoid questions about why she wasn't drinking alcohol:  
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3 One of the things I find really difficult about trying to conceive is you can't just go for a  
4 casual night out with friends and have drinks... I have tried going out and just drinking  
5 non-alcoholic drinks, but inevitably, someone tries to order another round or says, 'why  
6 don't you want to do this?' (II)  
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13 Another participant recalled missing out on a family get-together because a family  
14 member announced that she was pregnant at the event and she didn't want to show her family  
15 how upset she was: "I so distinctly remember sitting in my bedroom and just crying... I knew I  
16 couldn't leave our room." (FG)  
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23 **5.4. Feeling dismissed by health service providers.** Several participants recounted  
24 feeling disappointed with the service they had received from their mental health provider. One  
25 woman recounted her encounter with a mental health professional specializing in infertility: "She  
26 gave me quite a cookie cutter approach to her counseling... like, you're going through infertility  
27 so you must be experiencing this and this and this. I was like 'oh no I am not experiencing that.'"  
28 (II). In addition, women described feeling dismissed by their reproductive healthcare service  
29 providers who sometimes minimized the emotional pain associated with what they were  
30 experiencing. One woman seeking care for a suspected miscarriage remembered:  
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42 My family doctor... he told me he didn't think I was miscarrying, he also said, 'If you  
43 are, then it's not really a big deal because you're young and you can keep trying. I've had  
44 patients that have been trying for years and years and years and you really shouldn't be  
45 worried yet'. And that's really difficult and frustrating to hear. (II)  
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51 Mental health professionals echoed the same sentiments, remarking that younger women  
52 are especially prone to receiving dismissive comments from the medical community:  
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3 Women with a female factor diagnosis who are very, very young often have a very hard  
4 time in the treatment process because they're often not taken seriously...I've heard many  
5 specialists tell them, 'You have lots of time, don't worry about it, it'll happen for you',  
6 which can be really quite dismissive of their feelings and their coping. (MHP)  
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13 **5.5. Summary.** Through this theme, it became clear that women's tendency to distance  
14 themselves from others and the activities they used to enjoy is partly related to a desire to avoid  
15 having to discuss their infertility with others, whom they generally found to be unhelpful in  
16 providing emotional support. Several women perceived a lack of compassion and understanding  
17 of the emotional aspects of infertility among both mental health and reproductive health  
18 professionals, leading them to feel truly alone in coping with their emotional pain.  
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## 27 **DISCUSSION**

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30 The purpose of the current study was to gain a deeper understanding of infertility-related distress  
31 to inform the development of an intervention that is better tailored to infertility and more  
32 effective than currently available ones. While some of the identified themes and sub-themes are  
33 common to mood and anxiety disorders unrelated to infertility, the results of the current study  
34 also highlighted several challenges that are clearly unique to infertility. Women's reports,  
35 corroborated by the accounts of mental health professionals specializing in infertility-related  
36 distress, paint a picture of infertility-related distress in which one is highly preoccupied and  
37 emotionally invested in the day-to-day occurrences of the menstrual/treatment cycle, leading to  
38 high anxiety and fluctuating mood. As they are preoccupied with their current efforts and wish to  
39 avoid having to explain themselves to others or to submit themselves to others' pregnancies and  
40 children, they become more reclusive and spend less time engaged in activities that previously  
41 enriched their lives. They worry about who they will be and what their lives will look like if they  
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3 never conceive. At the same time, at home, women are struggling to connect with their partner as  
4 they do not always find themselves to be on the same page with regards to various reproductive  
5 events and/or decisions to be made. In a subset of women, these emotional struggles, contribute  
6 to clinical mental health problems over time and, in some, the complete dissolution of their  
7 relationship. While this description of the contributors and consequences of infertility-related  
8 distress paints a bleak picture, it serves a vital purpose: to directly inform the identification of  
9 therapy techniques that may help to target the specific identified challenges. Thus, below, in  
10 addition to comparing our findings to those of similar studies, we will discuss a number of  
11 psychotherapeutic interventions that may hold promise in directly targeting the unique  
12 components of infertility-related distress.  
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27 Anxiety emerged as one of the most prominent features of infertility-related distress,  
28 consistent with previous findings from other studies in which anxious rumination was reported to  
29 be a common feature of infertility (22, 23). A few studies have also reported on women's  
30 narrowed focus on infertility to the exclusion of other activities, as well as excessive information  
31 seeking as behavioral features of anxiety (24-26). In this study, these subthemes were more  
32 prominent, and we suspect that the inclusion of mental health professionals, providing an  
33 outsider's perspective, was a unique feature in the current study that may have facilitated the  
34 identification of these subthemes.  
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46 With regards to the second theme, mood disturbance, other researchers have also reported  
47 on the 'emotional rollercoaster' of infertility, as well as the loss of control that women frequently  
48 experience (6, 22, 27, 28). Emotional exhaustion and burnout have also been reported as a  
49 common feature of infertility, resulting from the chronic exposure to the emotional ups and  
50 downs of infertility (26, 29). This finding is consistent with the high rate of clinical depression  
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3 seen among women struggling with infertility (7, 9, 10). The third theme – threat to self-esteem,  
4 identity and purpose – is somewhat similar to previous reports that women’s view of themselves  
5 and their future identities are challenged by infertility, leading to feelings of role loss or role  
6 failure and the development of a negative self-perception (6, 26, 27). Pedro & Andipatin (2014)  
7 also reported on women’s tendency to blame themselves for their infertility (30). Finally, the  
8 broad themes of deterioration of the couple (22, 23, 28), and of weakened social support systems  
9 (27, 28) have been previously identified, though the identification of specific sub-themes within  
10 these broader issues is unique to the current study and helps to inform the identification and  
11 development of more effective psychotherapies directly targeting infertility-related distress. The  
12 sub-theme relating to negative interactions with healthcare providers adds to the findings of  
13 previous studies (31, 32) and highlights the need for increased education among healthcare  
14 providers in addressing the emotional aspect of infertility with sensitivity and compassion.  
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31 In examining the existing literature of psychological treatments that have been applied to  
32 infertility, cognitive restructuring, progressive muscle relaxation, and mindfulness meditation  
33 emerge as some of the most-used and tested approaches to date (15). While perhaps beneficial,  
34 the current findings suggest multiple other techniques that may further improve emotional  
35 wellbeing for this population. For example, given the prominence of anxious rumination and  
36 excessive information seeking, the incorporation of ‘worry time’ may be warranted. ‘Worry  
37 time’ is a technique that is commonly used in CBT for Generalized Anxiety Disorder and  
38 involves having the client set aside a certain amount of time daily (e.g., 30 minutes once or twice  
39 daily) to devote to their ongoing worries (33, 34). In the context of infertility, this time could be  
40 used to research potential treatments, budget for fertility treatments, or simply contemplate what  
41 life might be like without children. Whenever an infertility-related worry pops up outside of  
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3 ‘worry time’, women would be encouraged to jot down their concerns on a notepad, to be  
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5 considered further during the next worry time. While this technique may seem counter-intuitive,  
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7 research has found it to be effective in reducing the amount of time spent ruminating overall (33,  
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9 34).

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13 Reducing avoidance of reminders of others’ fertility, with the aim of reducing distress  
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15 triggered by these reminders, may also be a clinical target for future interventions. One technique  
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17 aimed at reducing avoidance is graduated exposure, a highly effective approach that is integral to  
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19 CBT for phobias (35). In the context of infertility, graduated exposure would involve having the  
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21 client create a hierarchy of upsetting stimuli (e.g., ranging from a diaper commercial to being in  
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23 the same room as a pregnant friend) and, little by little, having her expose herself to those stimuli  
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25 until the distress associated with it dissipates. At first, clients are often accompanied by a  
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27 therapist or other loved one who can provide emotional support. Acceptance and Commitment  
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29 Therapy (ACT) also directly targets avoidance by encouraging women to engage in activities  
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31 that align with their values, in spite of the distress that doing so may cause (36). For example, a  
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33 woman who highly values being a supportive sister will be encouraged to work up to going to  
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35 her sister’s baby shower. Importantly, cognitive strategies and mindfulness exercises are first  
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37 introduced to equip clients with the tools needed to cope with the distress they encounter through  
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39 the process of exposure. To our knowledge, avoidance has not been directly targeted in currently  
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41 available psychological interventions for infertility.  
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48 One therapeutic approach that seems to map on well to both shame/self-blame and  
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50 severed relationships with others is loving-kindness meditation (LKM) (37). LKM is a Buddhist  
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52 practice aimed at increasing compassion towards self and others. As a first step, one meditates  
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54 while focusing on statements that promote self-love and self-compassion (e.g., May I be free  
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3 from mental suffering or distress.) while attempting to let go of any self-judgment or self-hatred.  
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5 Next, thoughts and statements center around an elderly loved one, then a close loved one, next a  
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7 neutral person, and, finally, someone with whom you have a difficult relationship or feel  
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9 bitterness towards. Mounting research (38) suggests that LKM increases both positive self-regard  
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11 as well as positive feelings towards others. In infertility, it may therefore be used to reduce  
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13 feelings of shame related to the diagnosis while also improving relationships with others who fail  
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15 to provide the emotional support that was expected or hoped for.  
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20 Interpersonal psychotherapy (IPT) may also be an effective approach to improving a  
21  
22 woman's interpersonal relationships within the context of infertility. IPT is a time-limited,  
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24 evidence-based therapy that uses techniques such as communication analysis and role-playing to  
25  
26 address four main interpersonal issues: interpersonal disputes, role transitions, grief, and  
27  
28 interpersonal deficits (39, 40). Within the context of infertility, interpersonal disputes may  
29  
30 include disagreements with one's partner about next steps to take in fertility treatments or  
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32 negative interactions with loved ones who inadvertently make unhelpful comments. 'Role  
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34 transitions' may also be relevant for women contemplating stopping treatments and who are  
35  
36 trying to make peace with living a child-free life. Finally, 'grief' is clearly applicable to negative  
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38 pregnancy test outcome or miscarriage. To our knowledge, a single pilot study has tested IPT for  
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40 infertility-related distress with promising results (41).  
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46 A few limitations are worth mentioning. Our sample was relatively homogeneous, being  
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48 largely White and of high socioeconomic status, potentially limiting the generalizability of our  
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50 findings to the larger population. All participants were also in heterosexual relationships, perhaps  
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52 preventing the discovery of themes specific to same-sex couples. Despite these limitations, our  
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3 study is strengthened by its patient-oriented approach and its inclusion of mental health  
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5 professionals specializing in infertility.  
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9 Ultimately, it is hoped that the careful consideration of the unique aspects of infertility-  
10 related distress will result in the most effective intervention possible for this population. The  
11 findings of the current study highlight the need to address individuals' struggles with anxiety and  
12 depressive mood while also repairing fractured couple and interpersonal relationships,  
13 facilitating continued engagement in activities that enriched one's life before the diagnosis of  
14 infertility and that help to increase resilience in the face of the stressful circumstances  
15 surrounding infertility.  
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24  
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5

6 **Data availability statement:** The data (transcripts and audios files) for this study cannot be  
7  
8 made available to the public due to ethical reasons. However, the original data is reflected in the  
9  
10 results which provide a rich and thick description of the contents of the interviews through  
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12 quotations.  
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**Completed COREQ Checklist**

	Item	Description
<b>Domain 1: Research team and reflexivity</b>		
<i>Personal characteristics</i>		
1.	Interviewer/facilitator	The first & second author conducted the interviews
2.	Credentials	PhD
3.	Occupation	Research fellow and Associate professor
4.	Gender	Females
5.	Experience and training	PhD researchers
<i>Relationship with participants</i>		
6.	Relationship established	For this study, there was no relationship between the participants and the researchers before the commencement of the study.
7.	Participant knowledge of the interviewer	The participants were informed that the researchers were doing the research in order to identify the unique psychological challenges that they face, and that the findings will assist in the development of a treatment manual tailored for infertility distress.
8.	Interviewer characteristics	The interviewers are both PhD researchers with social work (1 <sup>st</sup> author) and clinical psychologist (4 <sup>th</sup> author) backgrounds.
<b>Domain 2: Study design</b>		
<i>Theoretical Framework</i>		
9.	Methodological orientation and Theory	Our study is a qualitative study (Page 5). This study employed a qualitative approach using semi-structured interviews to explore the experiences of women and mental health participants. In a qualitative approach, the aim is to provide an in-depth socio-contextual and detailed description and interpretation of the topic of the research topic.
<i>Participant selection</i>		
10.	Sampling	Purposive and snowball sampling strategies were used to recruit both women and mental health professionals (MHP) (see page 5).
11.	Method of approach	To recruit women, flyers were posted in a local fertility clinic and an advertisement was posted on the Facebook page of a local infertility support group. (see page 5)

		Eligible mental health professionals were identified via a broad internet search of clinicians affiliated with or endorsed by an infertility clinic, and clinicians in private practice advertising a specialization in infertility. Those identified through the search were invited via email to participate. (see page 6)
12.	Sample size	Women =2: Data saturation was achieved after the 21 <sup>st</sup> interview and data collection was stopped (page 8)  MHP = 14: Fourteen consented to participate in the study and completed the telephone interview. Eight mental health professionals were registered psychologists (4 PhD and 4 Masters), 3 were registered psychotherapists (1 PhD and 2 Masters), and 3 were registered social workers (Masters). (Page 9).
13.	Nonparticipation	N/A
<i>Setting</i>		
14.	Setting of data collection	Face to face interviews and focus group discussions were conducted at the research site at the University of Regina. Other interviews were conducted over the phone. Page 6.
15.	Presence of non-participants	N/A
16.	Description of sample	See Table 2: Demographic characteristics of women participants. (Page 9)
<i>Data collection</i>		
17.	Interview guide	Data was collected using two semi-structured interview guides (one for women and one for mental health professionals). The first interviews were pilot tests in order to refine the interview guides and the data was included in the analysis. (Page 6).  Refer to Table for examples of questions (Page 7).
18.	Repeat interviews	N/A
19.	Audio/ visual recording	Audio recording: All participants gave consent to be audio recorded. (Page 6)
20.	Field notes	The researchers took field notes (page 7).

21.	Duration	The length of each interview ranged from 30 minutes to 100 minutes, with an average of 60 minutes. (Page 10).
22.	Data saturation	Data saturation was achieved after the 21 <sup>st</sup> interview and data collection was stopped (see page 8).
23.	Transcripts returned	Transcripts were not returned to participants, but accuracy of information was done by paraphrasing and summarizing during interviews (page 7).
<b>Domain 3: Analysis and findings</b>		
<i>Data analysis</i>		
24.	Number of data coders	Preliminary data analysis was concurrent with data collection and was conducted by LD. The main data analysis was conducted by two independent authors, LD and NNM. JLG acted as an auditor of the data. (Page 8).
25.	Description of the coding tree	We provided the Table with categories and themes (see page 11).
26.	Derivation of themes	We used content analysis and themes were identified from the data (see page 8).
27.	Software	We used NVivo Software, see page 8.
28.	Participant checking	Member checking was achieved by paraphrasing and summarizing the participant's contributions during focus groups and interviews. (page 7).
<i>Reporting</i>		
29.	Quotations presented	Yes, pages 10-23.
30.	Data and findings consistent	Yes, pages 10-23
31.	Clarity of major themes	Yes, page 10-23.
32.	Clarity of minor themes	N/A

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## Infertility distress and clinical targets for psychotherapy: A qualitative study

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## Infertility distress and clinical targets for psychotherapy: A qualitative study

Loveness Dube<sup>1</sup>, PhD,  
Nokuthula Nkosi-Mafutha<sup>2</sup>, PhD,  
Ashley A. Balsom<sup>1</sup>, M.A.,  
Jennifer L. Gordon<sup>1</sup>, PhD\*

### Authors' Affiliation:

<sup>1</sup>Department of Psychology, University of Regina, Regina, Saskatchewan, Canada.

<sup>2</sup>Department of Nursing Education, University of the Witwatersrand, Johannesburg, South Africa

**ORCID IDs:** Loveness Dube: 0000-0002-0446-0608; Nokuthula Nkosi-Mafutha: 0000-0002-3227-1775; Ashley Balsom: 0000-0002-1795-8093; Jennifer Gordon: 000-0001-6401-6827

**\*Corresponding author at:** Department of Psychology, University of Regina, 3737 Wascana Pkwy, Regina, SK S4S 0A2, Regina, Saskatchewan, Canada. Email:

[jennifer.gordon@uregina.ca](mailto:jennifer.gordon@uregina.ca)

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## Abstract

**Objectives:** An estimated 30-40% of women attending infertility tertiary care facilities experience clinically significant depression and anxiety. However, current psychological interventions for infertility are only modestly effective in this population. In this study, we aimed to identify the specific psychological components of infertility-related distress to assist in the development of a more targeted and effective therapeutic intervention.

**Design:** A qualitative approach using semi-structured individual interviews and focus group interviews with women who have experience with infertility and also mental health professions specializing in the field of infertility. Thematic analysis was used to identify patterns and themes emerging from the data.

**Participants:** Twenty-one women (aged 25-41 years) struggling to conceive for  $\geq 12$  months and 14 mental health professionals participated in semi-structured interviews about the psychological challenges related to infertility.

**Results:** Five themes, each divided into subthemes, emerged from the data and these were developed into a model of infertility-related distress. These five themes are: (1) anxiety, (2) mood disturbance, (3) threat to self-esteem, identity and purpose, (4) deterioration of the couple, and (5) weakened support network. In addition, therapeutic techniques used by mental health professionals were identified.

**Conclusions:** The results of this study suggest specific clinical targets that future interventions treating infertility-related distress should address.

**Key words:** Mental health; Qualitative research; Reproductive medicine.

### Strengths and limitations of this study

- The study adopted a patient-oriented approach and included interviews with mental health professionals specializing in infertility.
- The qualitative approach provided an in-depth socio-contextual and detailed description and interpretation of the experiences of the infertile women.
- The study used different methods of triangulation in data collection (interviews and focus groups) and in sources of data (women and mental health professionals), which contributed to enrich the data.
- All participants were in heterosexual relationships, perhaps preventing the discovery of themes specific to same-sex couples.

## INTRODUCTION

Globally, 15% of couples are affected by infertility (1, 2), typically defined by the failure to achieve a clinical pregnancy after 12 months or more of regular unprotected sexual intercourse (3). While male and female factor infertility are roughly equivalent in prevalence (4), it is well documented that women generally bear the brunt of infertility-related burden, both physically and mentally, regardless of the cause (5, 6). In fact, research suggests that an estimated 30-40% of women attending infertility tertiary care facilities experience clinically significant depression and anxiety (7-10) and the rates are equally high in non-treatment seeking infertile women (11). At least half of infertile women have described infertility as the most upsetting event of their lives and their distress has been found to be comparable to that of people with other chronic diseases like cancer (12). Infertile women also reported feelings of shame, self-blame, grief, loss, anger, sadness, and lack of femininity (13, 14).

Despite the high rates of distress in this population, one meta-analysis suggests that current psychological interventions – most of which are merely modified versions of existing therapeutic approaches targeting general depression and anxiety – are only modestly effective in this population (15). Though they were found to result in small reductions in anxiety, they were not found to improve depressive symptoms, infertility distress or marital functioning when adjusting for publication bias. Furthermore, the overall effect size associated with randomized controlled trials of psychological interventions on combined psychological outcomes was non-significant and efficacy was not found to differ according to intervention type. There is therefore a great need to develop a new psychological intervention that is more effective in reducing infertility-related distress. We propose to do so by starting with a careful look at the specific clinical targets that an infertility-specific intervention should address. The purpose of the current

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2  
3 study was, therefore, to identify the unique psychological challenges faced by women struggling  
4 with infertility as well as identify other psychotherapeutic approaches that have yet to be used in  
5 the treatment of infertility-related distress. We therefore aimed to interview both women  
6 themselves and mental health professionals that specialize in treating this population. An  
7 inductive approach was then taken to identify the major themes and sub-themes characterizing  
8 infertility-related distress as well as to identify the major therapeutic approaches used by mental  
9 health professionals in treating this condition.

## 19 **METHODS**

### 22 **Study design**

25 This study employed a qualitative approach using semi-structured interviews to explore  
26 the experiences of women and mental health professionals. The qualitative approach was chosen  
27 with the aim of providing in-depth socio-contextual, detailed description and interpretation of the  
28 psychological challenges faced by infertile women (16).

### 35 **Patient and public involvement**

38 A panel of six women who were not study participants and who had experience with  
39 infertility collaborated with the researchers at two stages in this research. First, at the  
40 development of semi-structured interview guides and second, during the final stages of data  
41 analysis in the naming of the themes and sub-themes.

### 48 **Participants and sampling**

51 The target population included 1) women who were experiencing either primary or  
52 secondary infertility and 2) mental health professionals specializing in the field of infertility.  
53 Purposive and snowball sampling strategies were used to recruit both women and mental health  
54 professionals.

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3 professionals (17). To recruit women, flyers were posted in a local fertility clinic and an  
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5 advertisement was posted on the Facebook page of a local infertility support group. Eligible  
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7 participants were 18 years or older and had personal experience with infertility.  
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10 Eligible mental health professionals included Masters and PhD-level clinical  
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12 psychologists, counseling psychologists, and social workers throughout Canada and the United  
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14 States of America who had a self-reported specialization in infertility. Eligible mental health  
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16 professionals were identified via a broad internet search of clinicians affiliated with or endorsed  
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18 by an infertility clinic, and clinicians in private practice advertising a specialization in infertility.  
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20 Those identified through the search were invited via email to participate.  
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### 25 **Setting**

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28 Face to face interviews and focus group discussions were conducted at the research site at  
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30 the University of Regina. Other interviews were conducted over the phone.  
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### 33 **Data collection**

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36 Data was collected using two semi-structured interview guides (one for women and one  
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38 for mental health professionals). The first interviews were pilot tests in order to refine the  
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40 interview guides and the data were included in the analysis. Table 1 shows an example of  
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42 questions included in both interview guides. Demographic information was collected via an  
43  
44 online survey in Qualtrics (Qualtrics Inc., 2019) (18) for women with infertility and at the start of  
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46 the phone interview for mental health professionals. Focus group discussions for women  
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48 participants were chosen as a preferred method of data collection as they encourage participants  
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50 to explore topics that are seldom discussed (19), though the option of an individual interview was  
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52 provided for those preferring to maintain privacy. Telephone interviews were conducted only  
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3 when face-to-face interviews were not logistically possible. All mental health professional  
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5 interviews were conducted by phone. Data for both women and mental health professionals was  
6  
7 collected until saturation was achieved (i.e. new information was no longer generated).  
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11 Focus group interviews lasted 2 hours and individual interviews (face-to-face and  
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13 telephone) lasted between 40 and 60 minutes. Two moderators were present during focus group  
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15 interviews, one facilitating the discussion, and the other as an observer and note taker. LD  
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17 conducted all individual interviews with women. The length of each professional interview  
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19 ranged from 30 to 100 minutes, with an average of 60 minutes. Member checking was achieved  
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21 by paraphrasing and summarizing the participant's contributions during focus groups and  
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23 interviews. The researchers took field notes, and all interviews were audio recorded and  
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25 transcribed for thematic analysis.  
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### 30 **Data analysis**

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33 We followed the Consolidated criteria for reporting qualitative studies (COREQ) to  
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35 comprehensively report on important features of a qualitative study (20). Preliminary data  
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37 analysis was concurrent with data collection and was conducted independently by LD and NNM.  
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39 This analysis provided a means of determining data saturation through consensus from both  
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41 authors. The main data analysis was conducted independently by two authors, LD and NNM.  
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43 JLG acted as an auditor of the data. Interview transcripts for women and for mental health  
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45 professionals were analysed separately before comparing the emerging themes from the two  
46  
47 groups. Disagreements in the analysis process were discussed and resolved by consensus. We  
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49 adapted the phases of theme development as described by Vaismoradi (2016) to enable us to do a  
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51 thematic analysis that also resonates well with the steps of qualitative content analysis (16). The  
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53 thematic analysis was conducted in 4 phases, including initialization (reading transcriptions and  
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3 highlighting meaning units, coding and looking for abstractions in participants' accounts, writing  
4 reflective notes, classifying and comparing), construction (labelling, translating and  
5 transliterating, defining and describing, immersion and distancing), rectifying (relating themes to  
6 established knowledge, stabilizing), and finalization (developing the storyline) (16). Final  
7 decisions about the naming of themes and subthemes were made in collaboration with the panel  
8 of women who had helped prepare the interview guides, mentioned above. Although we used  
9 different data sources (women and professionals) and data collection techniques (individual  
10 versus focus group interview), the same themes related to women's experiences emerged in the  
11 analysis. It was therefore decided that the results from both data sources and data collection  
12 methods would be merged, where applicable. NVivo (NVivo 12) software was used to facilitate  
13 data management, coding and analysis (QSR International Pty Ltd., 2019) (21).

## 30 RESULTS

31  
32 Thirty-three women responded and met eligibility criteria. Two focus groups of 4  
33 participants each, 7 individual face-to-face interviews, and 6 individual telephone interviews  
34 were conducted. After 21 women had been interviewed, data saturation was achieved, and data  
35 collection was stopped. Table 2 shows the demographic characteristics of the women  
36 participants.

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39 Of the 121 mental health professionals contacted, 16 responded. Fourteen consented to  
40 participate in the study and completed the telephone interview. Eight participants were registered  
41 psychologists (4 PhD and 4 Masters), three were registered psychotherapists (1 PhD and 2  
42 Masters), and three were registered social workers (Masters). All mental health professionals  
43 were women and most practitioners worked in private practice. All had at least two years of  
44 experience, while 75% had at least five years of experience.

## Psychological experiences of women

Although data were analyzed separately for women and health professionals, the themes and subthemes emerging from both groups relating to the psychological experiences of women proved to be very similar and are presented together. Findings from this study illuminated five important themes for the psychological experiences of women, which were developed into a model of infertility-related distress. These five themes are: (1) anxiety, (2) mood disturbance, (3) threat to self-esteem, identity and purpose, (4) deterioration of the couple, and (5) weakened support network (Figure 1). In the following section, themes will be discussed in detail, with supporting quotations provided from different participants, referenced with the following abbreviations where needed: individual interview (II), focus group (FG) and mental health professional (MHP).

### 1. Anxiety

Anxiety was perhaps the most highly endorsed aspect of infertility-related distress. Both the mental health professionals and women described relentless anxiety manifesting itself through multiple behaviors, described below, aimed at seeking reassurance and avoiding further distress.

**1.1. Anxious rumination.** Women with infertility reported anxiously thinking about their infertility, often to the point of “obsession”. Both the women and mental health professionals described women’s incessant thoughts about the causes and treatment of their infertility and monitoring of their menstrual cycle and symptoms that might indicate pregnancy, to be all consuming. One woman reflected: “I was developing a lot of anxiety and spending so much time hovering about this like it was just becoming completely all consuming”. (FG) One health professional considered anxiety to be the most prominent feature of infertility-related distress:

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3 One of the primary emotional symptoms is anxiety... rumination over the uncertainty,  
4 and anxiety sometimes about the medical procedures, anxiety related to going to the  
5 fertility clinic... Anxiety related to just not knowing. (MHP)  
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10 **1.2 Avoidance of fertility reminders.** Many women reported feeling the need to avoid  
11 activities and social events that would expose them to reminders of others' fertility, such as  
12 family gatherings where pregnant women, children, and babies would be present. Women also  
13 described avoiding social media to avoid seeing pregnant persons and birth announcements:  
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19 And then all of a sudden, birth announcements... pregnancy announcements start to  
20 bother you... You don't want to go on your social media because you just don't want to  
21 see everybody having fun with their babies and their families and getting pregnant... and  
22 you just feel like you're left behind. (II)  
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29 Mental health professionals also reported this avoidance as a frequently observation.  
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31 "Everything and everyone can be very triggering", said one. Both women and professionals  
32 linked this avoidance of potentially triggering social situations with a gradual increase in social  
33 isolation and distancing from once-close friends and family members.  
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39 **1.3. Narrowed focus on fertility related activities.** It was mostly mental health  
40 professionals who made observations related to this sub-theme by mentioning that, over time,  
41 women would increasingly focus on their attempts to conceive at the cost of their previously  
42 enjoyed activities. Events and plans would be put on hold for the sake of their treatments or 'in  
43 case' they became pregnant. The professionals also explained that, over time, getting pregnant  
44 often became the topic of every conversation within a couple and all actions and activities were  
45 solely focused on conceiving and the next steps in the process:  
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3 Fertility treatment becomes everything, it consumes their everyday life...A tendency for  
4 couples going through fertility [treatments] or struggling with infertility is that that's all  
5 they talk about, fertility and next steps. (MHP)  
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10 Relatedly, one woman explained that the scheduling of fertility treatments often made it  
11 difficult to plan:  
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16 I hate that I can't plan stuff because we are still doing IVF [in-vitro fertilization], we  
17 have embryos that are still on ice. And so, every try is three months apart and we love to  
18 travel but it's like you can't book because you don't know when exactly that next  
19 treatment is.... It's just that lack of being able to plan. (FG)  
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26 **1.4. Excessive information seeking.** Spending an excessive amount of time seeking  
27 information about the causes and potential treatment of infertility, usually via the internet, was  
28 described by both women and mental health professionals: "Sometimes I do see... pure  
29 obsession, it can actually look like where the person is frantically researching online repeatedly  
30 for explanation as to why they haven't gotten pregnant." (MHP) Health professionals also voiced  
31 concerns that this constant searching for answers was potentially harmful for women as the  
32 information they obtained was often of questionable validity.  
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43 **1.5. Summary.** Every woman and health professional interviewed emphasized elements  
44 of anxiety related to infertility. Women who had undergone fertility treatments related their  
45 anxious rumination to the success of the many procedures involved in the treatment process  
46 while women who had only struggled to conceive without medical intervention reported being  
47 very focused on the different phases of their menstrual cycle, identifying signs of fertility, and  
48 looking for signs that a cycle was positive. This excessive mental energy devoted to all things  
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3 infertility, coupled with a desire to avoid witnessing evidence that others are conceiving without  
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5 difficulty, resulted in a decreased engagement in previously enjoyed activities and an increase in  
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7 social withdrawal. Anxiety as a theme was more prominent in focus groups and face-to-face  
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9 interviews when compared to interviews conducted over the phone. We hypothesize that perhaps  
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11 researchers were better able to build rapport in face-to-face interactions, allowing women to feel  
12  
13 more comfortable sharing their challenges.  
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## 16 17 18 **2. Mood disturbance**

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20 This theme captured women's experience of enormous fluctuations between positive and  
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22 negative emotion, eventually leading to complete exhaustion and, in some cases, depression.  
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26 **2.1. Emotional lability.** As common as the confirmation of anxiety was the description  
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28 of infertility as an "emotional rollercoaster": at the start of each cycle, hope and excitement  
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30 would build, only to be met with extreme disappointment and grief following each negative test  
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32 or miscarriage:  
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36 Every month, you go through this cycle of excitement or hope and then followed by no  
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38 success... You get depressed, you get very discouraged or very down...and then you  
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40 think, 'Oh, I'm not going to invest any more energy', but then just by nature, you do. And  
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42 then you get hopeful and excited again, and you just go through this rollercoaster of  
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44 emotions that way. (II)  
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48 Women who had undergone fertility treatments explained that their mood was highly  
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50 dependent on the outcomes of each step in fertility treatments: ultrasounds, egg retrieval, and  
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52 embryo transfer. Some women also reported that the hormones taken for infertility exacerbated  
53  
54 their emotional lability: "The hormones that they have you on wreak havoc with my entire being,  
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3 I felt crazy.” (FG2) Other women reported being overly sensitive or irritable in their daily lives  
4  
5 because of their high stress levels, directly related to their struggles to conceive.  
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9 **2.2. Helplessness.** Several women stated that one of the biggest challenges related to  
10 infertility was the feeling of being completely helpless in the process of trying to conceive.  
11  
12 Women reported feeling extremely frustrated by their lack of control over the outcome of any  
13 given cycle. One woman participating in a focus group lamented: “One of the hardest aspects is  
14 the helplessness that I feel...because most of the things in my life - it's like okay, you do A B C  
15  
16 D and you get this outcome but with this there's just no guarantees.”  
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23 One participant explained that the sense of a lack of control over the process led her to  
24 even contemplate not taking her medication so that she could at least have “some sense of  
25 control over destiny”. Women also expressed frustration at the lack of information and choice  
26 regarding their treatment options: “I feel like they have a very set order [in fertility clinics but]  
27 they are not going to tell you why this is the order in which they do things.” (FG) Mental health  
28 professionals similarly remarked that women were given little opportunity to determine the  
29 course of their treatment in medical settings.  
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40 **2.3. Emotional exhaustion.** Women participants reported that the constant alternation  
41 between hope and despair, along with their feelings of helplessness, led them to become  
42 emotionally drained. One woman explained that fertility treatments had drained her to the point  
43 of requiring a mental health break from work: “I went to the doctor and I said to her, ‘I need to  
44 get off work, I need to be on stress leave because I can't do this anymore.’” (II) Another woman  
45 recalled a time when she had “hit rock bottom” and became suicidal because of her difficulties  
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3       **2.4. Summary.** Nearly all women reported that their mood dipped at certain points  
4  
5 throughout their cycle each month, particularly after a negative outcome. Feelings of complete  
6  
7 helplessness over the process and outcome of each cycle was also very prominent. A smaller  
8  
9 subset of women, however, related the constant up and down from hope to despair to the  
10  
11 development of emotional exhaustion and what sounds like clinical depression.  
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### 14 15 **3. Threat to self-esteem, identity and purpose**

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18       This subtheme captured women's reports that infertility had contributed to a questioning  
19  
20 of their identity and negative internal dialogue about their worth and the worth of their life in the  
21  
22 absence of motherhood.  
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26       **3.1. Unmet expectations for self and one's future.** Many of the women reported an  
27  
28 enormous sense of loss as they reflected on their childhood dreams of being a mother. One  
29  
30 woman remembered:  
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32

33       When I was a kid, I wasn't dreaming about being a doctor or vet or thinking about the  
34  
35 perfect wedding, I was thinking about being a mom. And it was just a sense that the  
36  
37 vision of what I had for my future wasn't possible. (FG)  
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41       Mental health professionals added that for many women, motherhood was so closely tied  
42  
43 to their identity as a woman that their infertility diagnosis threatened their very sense of who they  
44  
45 were as a person:  
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48       The number one thing that I see and can identify hands down is there is an attack on their  
49  
50 identity and their sense of self, the narrative that they believed about who they were, what  
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52 their reproductive story was, and they feel very shattered from that because this story is  
53  
54 not playing out. (MHP)  
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3 Health professionals also reported that women having to pursue third-party reproduction  
4 also grieve the loss of pregnancy in the case of surrogacy, and the loss of genetic connection to  
5  
6 their child in the case of egg donation.  
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11 **3.2. Self-blame.** Several women reported believing that they were partly to blame for  
12 their infertility, particularly among women with female factor infertility: “You have to deal with  
13 the mental aspect of knowing...that I was the reason that we didn’t have kids... If [my husband]  
14 was with someone else, he could be having those kids.” (II) Women also reported that they  
15 tended to question whether any of their behaviors might be contributing to their diagnosis or a  
16 failed cycle. One woman, a long-distance runner, recalled: “A few of my IUIs [intrauterine  
17 inseminations] were right after doing a very long race and so I felt like maybe that’s why it  
18 didn’t work. I was blaming myself that it didn’t work.” (FG) Mental health professionals  
19 corroborated these reports.  
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33 **3.3. Shame.** Many women reported feeling ashamed of their diagnosis of infertility,  
34 seeing themselves as “broken”, leading them to keep their struggles a secret or to share with only  
35 a few close others: “If I had cancer, it would have been open, and we could have talked about it  
36 and my community would have supported me. But when it's infertility, you feel different,  
37 isolated, and embarrassed, and ashamed” (II). Mental health professionals echoed the same  
38 sentiment, highlighting the difference between how infertility was perceived compared to other  
39 medical conditions.  
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50 **3.4. Summary.** Within this theme, we see that infertility often triggers an existential  
51 crisis of sorts: a profound questioning of what it means to be a woman in the absence of fertility  
52 and the potential for motherhood. Women were left wondering what their lives would look like  
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3 and what value it might have if motherhood was never achieved. This seems to be particularly  
4  
5 the case for women who reported having wanted to be a mother since childhood.  
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#### 8 **4. Deterioration of the couple**

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11 As one mental health professional reported, some relationships were strengthened by the  
12  
13 process of struggling to conceive while others suffered to the point of divorce. The following  
14  
15 challenges, however, appeared to be common even among couples whose relationship was  
16  
17 strengthened overall.  
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21 **4.1. Partner differences in coping.** Women described their frustration related to  
22  
23 differences in coping between themselves and their partners. It appears that women often took a  
24  
25 more active role and expressed their emotions more openly than their partners, leading them to  
26  
27 perceive their partners as being less emotionally invested in the goal of conceiving:  
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31 It makes me feel like I'm the one that's always worrying and stressing and thinking about  
32  
33 things and making appointments and tracking my cycle and kind of carrying the burden  
34  
35 in a way...He's just kind of very laid-back about the situation...it gets a little frustrating  
36  
37 for me. (II)  
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41 Another woman reflected on her and her husband's different ways of coping with grief  
42  
43 following a miscarriage:  
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47 The first time the miscarriage happened, my husband kind of grieved separately because  
48  
49 he didn't want to grieve in front of me because he thought that it wouldn't help how I was  
50  
51 doing with it...so I just thought like, 'Hey, we had a miscarriage, and he's fine.' (II)  
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3 Mental health professionals agreed that many challenges within the couple related to  
4 partners not ‘processing’ events surrounding infertility at the same pace.  
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8 **4.2. Negative impact on couple’s sex life.** Women commonly reported a deterioration of  
9 the couple’s sex life because, over time, the purpose of sex became solely to achieve conception  
10 rather than intimacy or enjoyment: “it just seems like work” (II). One mental health professional  
11 described sex as becoming “transactional” in nature and reported that women often found it  
12 difficult to engage without thinking about the goal of conceiving.  
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20 **4.3. Stress related to financial burden of fertility treatments.** Given the high costs of  
21 fertility treatments, for the most part not covered by medical insurance, women reported that  
22 strained finances became a prominent topic of conversation among couples pursuing assisted  
23 reproductive technologies:  
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30 Conversations around the cost of everything just because that puts a lot of strain on our  
31 relationship...How can we afford it?...How can we make it work? We don't really have  
32 time to wait and save up for this, we just have to figure it out now. (FG)  
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38 Concerns about finances would also lead to stressful discussions around the feasibility of  
39 continuing treatment. The same sentiment was echoed by the mental health professionals who  
40 described the financial strain brought on by fertility treatments as being a challenge for most  
41 couples.  
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47 **4.4. Couple disagreements on next steps.** A few women reported that tension within  
48 the couple arose due to differences in opinion about next steps to take in trying to conceive: “I  
49 got divorced because... I think he was done before I was, he just didn't want to do it anymore.”  
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3 (FG). One woman recalled that she and her husband went into a doctor's appointment with very  
4  
5 different intentions and expectations, which led to conflict afterwards:  
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8 "I went in thinking like, 'Okay, we're going to get the information and move forward.'  
9

10 He went in thinking, 'Okay, I'm going in to get the information and then make a decision  
11  
12 on that.' So, we were on different pages going in." (II)  
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16 **4.5. Summary.** While a few women reported that their relationships were strengthened  
17  
18 overall because of going through the challenges of infertility together, all women referred to  
19  
20 some difficulties within the couple at one time or another. A subset of women reported that their  
21  
22 relationship had been severely tested (or severed) by their struggles with infertility and these  
23  
24 serious conflicts seemed to be primarily related to differences in opinion regarding next steps to  
25  
26 take regarding treatment.  
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### 33 **5. Weakened social support network**

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36 The theme of weakened social support networks highlights women participants' struggles  
37  
38 with their loved ones due to stigma and lack of education surrounding infertility. Women also  
39  
40 reported that their experiences were often dismissed by health service providers.  
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44 **5.1. Strained relationships with friends and family.** Women explained that  
45  
46 relationships with friends and family were often strained in the context of infertility, in part due  
47  
48 to the barrage of unhelpful comments and questions they received from well-meaning loved  
49  
50 ones. One woman explained why she felt that she couldn't open up to her friends about her  
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52 infertility:  
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3 I have a lot of friends who mean well, and they just keep saying it'll happen...I just don't  
4 know what they want me to say to that... I feel like if I talk to them about it, they're just  
5 gonna be like, 'Oh just stay positive'. (FG)  
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11 Several women reported that their family members often showed a lack of understanding  
12 about the emotional pain they were experiencing, even when they were open with them about the  
13 challenges they were facing: "All my mom said was that I was a b\*\*\*\* that Christmas. And so,  
14 there was just no understanding." (FG) Participants also struggled with feelings of envy,  
15 jealousy, and resentment towards friends or family who had conceived easily, which also  
16 contributed to distance with once-close loved ones:  
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25 The relationship with my brother is still pretty strained. Him and his wife actually ended  
26 up getting pregnant five weeks before I did, and they only tried for a couple of days...  
27 and then got pregnant right away. ...I felt like they didn't deserve their pregnancy  
28 because they didn't have to work for it. (II)  
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35 **5.2. Social stigma.** Women reported that they perceived a great amount of social stigma  
36 related to infertility, which created anxiety around discussing it openly: "I felt reluctant to tell  
37 friends and other people. And I still haven't told everyone in my life...just because I didn't want  
38 to be an object of pity, I didn't want anyone to think I was a barren woman." (II). Other women  
39 refrained from telling others about their infertility because they did not want to be judged by  
40 friends and family who might comment on the woman's potential role in contributing to her  
41 problems conceiving.  
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52 **5.3. Social isolation.** An increase in social isolation seemed to be a consequence of  
53 several processes – women's avoidance of fertility reminders (from theme 1), their attempts to  
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3 avoid unhelpful comments and questions from others, and the pressure to hide their  
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5 preoccupation with their infertility: “I feel like it kind of closed off some of my opportunities for  
6  
7 healthy, normal socialization...and I think to some extent, that's impeded my ability to form  
8  
9 closer relationships with people too.” (II) For example, one participant recounted avoiding get-  
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11 togethers at bars or pubs in order to avoid questions about why she wasn't drinking alcohol:  
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14  
15 One of the things I find really difficult about trying to conceive is you can't just go for a  
16  
17 casual night out with friends and have drinks... I have tried going out and just drinking  
18  
19 non-alcoholic drinks, but inevitably, someone tries to order another round or says, ‘Why  
20  
21 don't you want to do this?’ (II)  
22  
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25 Another participant recalled missing out on a family get-together because a family  
26  
27 member announced that she was pregnant at the event and she didn't want to show her family  
28  
29 how upset she was: “I so distinctly remember sitting in my bedroom and just crying... I knew I  
30  
31 couldn't leave our room.” (FG)  
32  
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35 **5.4. Feeling dismissed by health service providers.** Several participants recounted  
36  
37 feeling disappointed with the service they had received from their mental health provider. One  
38  
39 woman recounted her encounter with a mental health professional specializing in infertility:  
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43 She gave me quite a cookie cutter approach to her counseling... like, you're going  
44  
45 through infertility so you must be experiencing this and this and this. I was like ‘Oh no, I  
46  
47 am not experiencing that.’ (II)  
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51 In addition, women described feeling dismissed by their reproductive healthcare service  
52  
53 providers who sometimes minimized the emotional pain associated with what they were  
54  
55 experiencing. One woman seeking care for a suspected miscarriage remembered:  
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3 My family doctor... He told me he didn't think I was miscarrying. He also said, 'If you  
4 are, then it's not really a big deal because you're young and you can keep trying. I've had  
5 patients that have been trying for years and years and years and you really shouldn't be  
6 worried yet'. And that's really difficult and frustrating to hear. (II)  
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13 Mental health professionals echoed the same sentiments, remarking that younger women  
14 are especially prone to receiving dismissive comments from the medical community:  
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18 Women with a female factor diagnosis who are very, very young often have a very hard  
19 time in the treatment process because they're often not taken seriously...I've heard many  
20 specialists tell them, 'You have lots of time, don't worry about it, it'll happen for you',  
21 which can be really quite dismissive of their feelings and their coping. (MHP)  
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28 **5.5. Summary.** Through this theme, it became clear that women's tendency to distance  
29 themselves from others and the activities they used to enjoy was partly related to a desire to  
30 avoid having to discuss their infertility with others, whom they generally found to be unhelpful  
31 in providing emotional support. Several women perceived a lack of compassion and  
32 understanding of the emotional aspects of infertility among both mental health and reproductive  
33 health professionals, leading them to feel truly alone in coping with their emotional pain.  
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#### 42 **Therapeutic techniques used by mental health professionals**

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45 All the mental health professionals reported using an eclectic approach to psychotherapy  
46 for infertility. They combined techniques from a number of different therapeutic approaches,  
47 including but not limited to the following: supportive therapy, cognitive behavioural therapy  
48 (CBT), dialectical behavioural therapy (DBT), acceptance and commitment therapy (ACT),  
49 compassion focused therapy, mindfulness, counselling, eye movement desensitization and  
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3 reprocessing (EMDR), cognitive processing therapy (CPT), emotion-focused therapy (EFT),  
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5 solution focused therapy, psychodynamic therapy, interpersonal psychotherapy (IPT), internal  
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7 family systems (IFS), expressive therapy, existential therapy, and upside down therapy.  
8  
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10 CBT, DBT, and mindfulness-based approaches stood out as the most used, although  
11  
12 always in combination with others. Participants also reported applying CBT with caution: “At  
13  
14 times I might reach for CBT...but really I have to be very careful because...the distress that a  
15  
16 woman is experiencing...are a normal response to an abnormal situation.” (MHP 1) A second  
17  
18 mental health professional echoed these concerns: “There’s nothing more invalidating to a  
19  
20 woman who’s experienced multiple losses than when you sit down with her and would say, ...  
21  
22 ‘So, what are the cognitive distortions?’...It’s invalidating.” (MHP 1) Other mental health  
23  
24 professionals found that CBT was not at all useful in the context of infertility:  
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30 CBT and solution-focused [therapy] are pretty useless with this population...and I know  
31  
32 the evidence doesn’t support that because that’s the only theory [CBT] that has any  
33  
34 evidence-based research behind it, which creates its own bias in and of itself. (MHP 11)  
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37 Several mental health professionals reported using mindfulness techniques, particularly  
38  
39 for addressing anxiety, with one reporting: “We do a lot of emotion regulation and mindfulness  
40  
41 grounding and learning to breathe and settle their anxiousness.” (MHP 3) A second professional  
42  
43 stated: “Women really find it helpful to learn just ways of the balance between accepting, and  
44  
45 letting go, and having hope, and I think... that can be found through mindfulness.” (MHP 12)  
46  
47 Others reported combining a mindfulness approach with traditional CBT: “I often and typically  
48  
49 in practice use mindfulness and CBT together.” (MHP 13) Still others endorsed using  
50  
51 mindfulness in the context of other therapeutic approaches that include mindfulness as part of its  
52  
53 focus, including ACT and DBT, a CBT-based approach that incorporates mindfulness and other  
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3 skills aimed at promoting distress tolerance: “I use...DBT techniques because the amount of  
4  
5 distress that I see in these women is profound.” (MHP 14)  
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9 Several mental health professionals emphasized that flexibility was critical and that  
10 adherence to a therapeutic approach should not interfere with responding to a client’s needs in  
11 any given session. One therapist explained: “Client centered is so important...some people just  
12 want to be heard and validated, and that's why they're coming to therapy.” (MHP 7) Another  
13 expressed a similar sentiment: “everyone is different...looking at what are their goals... so very  
14 client-centered focus.” (MHP 9)  
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23 In sum, all mental health professional participants reported using techniques from more  
24 than one psychotherapeutic approach in order to address the psychological symptoms associated  
25 with infertility and to target the specific needs of each client.  
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## 30 **DISCUSSION**

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33 The purpose of the current study was to gain a deeper understanding of infertility-related  
34 distress as well as gather information about which psychotherapeutic approaches were being  
35 used by mental health professionals for the treatment of infertility-related distress. The ultimate  
36 aim was to inform the development of an intervention better tailored to infertility and more  
37 effective than currently available ones. While some of the identified themes and sub-themes are  
38 common to mood and anxiety disorders unrelated to infertility, the results of the current study  
39 also highlighted several challenges that are clearly unique to infertility. Women’s reports,  
40 corroborated by the accounts of mental health professionals specializing in infertility-related  
41 distress, paint a picture of infertility-related distress in which one is highly preoccupied and  
42 emotionally invested in the day-to-day occurrences of the menstrual/treatment cycle, leading to  
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3 high anxiety and fluctuating mood. As they are preoccupied with their current efforts and wish to  
4 avoid having to explain themselves to others or to submit themselves to others' pregnancies and  
5 children, they become more reclusive and spend less time engaged in activities that previously  
6 enriched their lives. They worry about who they will be and what their lives will look like if they  
7 never conceive. At the same time, at home, women are struggling to connect with their partner as  
8 they do not always find themselves to be on the same page with regards to various reproductive  
9 events and/or decisions to be made. In a subset of women, these emotional struggles contribute  
10 to clinical mental health problems over time and, in some, the complete dissolution of their  
11 relationship. Below, we review each of the identified themes in greater detail and compare our  
12 findings with those of other studies.  
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27 Anxiety emerged as one of the most prominent features of infertility-related distress,  
28 consistent with previous findings from other studies in which anxious rumination was reported to  
29 be a common feature of infertility (22, 23). A few studies have also reported on women's  
30 narrowed focus on infertility to the exclusion of other activities, as well as excessive information  
31 seeking as behavioral features of anxiety (24-26). In this study, these subthemes were more  
32 prominent, and we suspect that the inclusion of mental health professionals, providing an  
33 outsider's perspective, was a unique feature in the current study that may have facilitated the  
34 identification of these subthemes.  
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46 With regards to the second theme, mood disturbance, other researchers have also reported  
47 on the 'emotional rollercoaster' of infertility, as well as the loss of control that women frequently  
48 experience (6, 22, 27, 28). Emotional exhaustion and burnout have also been reported as a  
49 common feature of infertility, resulting from the chronic exposure to the emotional ups and  
50 downs of infertility (26, 29). This finding is consistent with the high rate of clinical depression  
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3 seen among women struggling with infertility (7, 9, 10). The third theme – threat to self-esteem,  
4 identity and purpose – is somewhat similar to previous reports that women’s view of themselves  
5 and their future identities are challenged by infertility, leading to feelings of role loss or role  
6 failure and the development of a negative self-perception (6, 26, 27). Pedro and Andipatin (2014)  
7 also reported on women’s tendency to blame themselves for their infertility (30). Finally, the  
8 broad themes of deterioration of the couple (22, 23, 28), and of weakened social support systems  
9 (27, 28) have been previously identified. However, the identification of specific sub-themes  
10 within these broader issues is unique to the current study and helps to inform the identification  
11 and development of more effective psychotherapies directly targeting infertility-related distress.  
12 The sub-theme relating to negative interactions with healthcare providers adds to the findings of  
13 previous studies (31, 32) and highlights the need for increased awareness and education among  
14 healthcare providers in addressing the emotional aspect of infertility with sensitivity and  
15 compassion.  
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34 Mental health professionals reported using an array of techniques borrowed from a range  
35 of psychotherapy approaches, some more evidence-based than others, to address the unique  
36 challenges associated with infertility-related distress. CBT, arguably the psychotherapeutic  
37 approach most supported by research evidence for the treatment of depression and anxiety  
38 unrelated to infertility (33) was met with disdain by some and cautious acknowledgement of its  
39 potential benefits by others. Specific concerns about CBT related to its focus on “cognitive  
40 distortions” as being invalidating of the very natural emotions resulting from infertility.  
41 Approaches incorporating mindfulness, commonly termed “third-wave” psychotherapy  
42 approaches, were mentioned numerous times as being helpful, including mindfulness-based  
43 cognitive therapy, dialectical behavioural therapy, and acceptance and commitment therapy, all  
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3 of which are supported by growing bodies of research evidence for distress unrelated to  
4 infertility (34-36). Other therapy approaches mentioned, such as emotion focused therapy, upside  
5 down therapy, and existential therapy, have modest to no research support as of yet (37).  
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11 These findings, in combination with recent meta-analytic evidence suggesting that the  
12 efficacy of current psychotherapeutic approaches to infertility is modest (15), perhaps reflect a  
13 need for a new psychotherapeutic approach that combines techniques from various approaches to  
14 create a more tailored intervention that addresses the unique psychological challenges identified  
15 here. While cognitive restructuring, progressive muscle relaxation, and mindfulness meditation  
16 are the most-used and tested approaches to date for the treatment of infertility-related distress,  
17 their efficacy in this population is limited (15). Several other approaches mentioned by the  
18 mental health professionals may better target the unique aspects of infertility-related distress. For  
19 example, some of the techniques used in DBT aimed at improving distress tolerance (35) may  
20 help women cope with intense distress during medical procedures or after very upsetting news.  
21 The interpersonal effectiveness skills taught in DBT may also help individuals appropriately  
22 interact with the people in their lives who say unhelpful or upsetting things related to their  
23 infertility.  
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41 Acceptance and Commitment Therapy (ACT), mentioned by several mental health  
42 professionals in our study, may be useful in addressing the avoidance of infertility reminders,  
43 which emerged as one of the subthemes of infertility-related anxiety, as ACT encourages women  
44 to engage in activities that align with their values, in spite of the distress that doing so may cause  
45 (36). For example, a woman who highly values being a supportive sister will be encouraged to  
46 work up to going to her sister's baby shower. Importantly, cognitive strategies and mindfulness  
47 exercises are first introduced to equip clients with the tools needed to cope with the distress they  
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3 encounter through the process of exposure. To date, studies conducted in the Middle East have  
4 applied ACT to infertility-related distress with promising results (38-40), though it has yet to be  
5 tested in North America.  
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11 Several of the mental health professionals highlighted the use of mindfulness-based  
12 approaches. Although mindfulness approaches have proven to be of limited efficacy for  
13 infertility-related distress, one mindfulness-based approach that has yet to be applied to infertility  
14 is loving-kindness meditation (LKM) (41), which seems to map on well to both shame/self-  
15 blame and severed relationships with others. LKM is a Buddhist practice aimed at increasing  
16 compassion towards self and others. As a first step, one meditates while focusing on statements  
17 that promote self-love and self-compassion (e.g., ‘May I be free from mental suffering or  
18 distress’), while attempting to let go of any self-judgment or self-hatred. Next, thoughts and  
19 statements center around an elderly loved one, then a close loved one, next a neutral person, and,  
20 finally, someone with whom you have a difficult relationship or feel bitterness towards.  
21 Mounting research (42) suggests that LKM increases both positive self-regard as well as positive  
22 feelings towards others. In infertility, it may therefore be used to reduce feelings of shame  
23 related to the diagnosis while also improving relationships with others who fail to provide the  
24 emotional support that was expected or hoped for.  
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44 Interpersonal psychotherapy (IPT), which was also mentioned by several mental health  
45 professionals, may also be an effective approach to improving a woman’s interpersonal  
46 relationships within the context of infertility. IPT is a time-limited, evidence-based therapy that  
47 uses techniques such as communication analysis and role-playing to address four main  
48 interpersonal issues: interpersonal disputes, role transitions, grief, and interpersonal deficits (43,  
49 44). Within the context of infertility, interpersonal disputes may include disagreements with  
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3 one's partner about next steps to take in fertility treatments or negative interactions with loved  
4 ones who inadvertently make unhelpful comments. 'Role transitions' may also be relevant for  
5 women contemplating stopping treatments and who are trying to make peace with living a child-  
6 free life. Finally, 'grief' is clearly applicable to negative pregnancy test outcome or miscarriage.  
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8 To our knowledge, a single pilot study has tested IPT for infertility-related distress, with  
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10 promising results (45).  
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18         Though CBT has been applied to infertility in a number of studies, with limited results,  
19 there are a number of CBT-based techniques that have yet to be used but that may address some  
20 of the specific infertility-related psychological challenges raised in this study. Specifically, given  
21 the prominence of anxious rumination and excessive information seeking, the incorporation of  
22 'worry time' may be warranted. 'Worry time' is a technique that is commonly used in CBT for  
23 generalized anxiety disorder and involves having the client set aside a certain amount of time  
24 daily (e.g., 30 minutes once or twice daily) to devote to their ongoing worries (33, 46). In the  
25 context of infertility, this time could be used to research potential treatments, budget for fertility  
26 treatments, or simply contemplate what life might be like without children. Whenever an  
27 infertility-related worry pops up outside of 'worry time', women would be encouraged to jot  
28 down their concerns on a notepad, to be considered further during the next worry time. While  
29 this technique may seem counter-intuitive, research has found it to be effective in reducing the  
30 amount of time spent ruminating overall (33, 46).  
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48         A few limitations are worth mentioning. Our sample was relatively homogeneous, being  
49 largely Caucasian and of high socioeconomic status, potentially limiting the generalizability of  
50 our findings to the larger population. All participants were also in heterosexual relationships,  
51 perhaps preventing the discovery of themes specific to same-sex couples. Despite these  
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3 limitations, our study is strengthened by its patient-oriented approach and its inclusion of mental  
4 health professionals specializing in infertility.  
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8 Ultimately, it is hoped that the careful consideration of the unique aspects of infertility-  
9 related distress will result in the most effective intervention possible for this population. The  
10 findings of the current study highlight the need to address individuals' struggles with anxiety and  
11 depressive mood while also repairing fractured couple and interpersonal relationships,  
12 facilitating continued engagement in activities that enriched one's life before the diagnosis of  
13 infertility and that help to increase resilience in the face of the stressful circumstances  
14 surrounding infertility.  
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26 mental health professionals who gave their invaluable time to contribute to this study. A special  
27 thanks goes to the panel of women and the team at the Women's Mental Health Research lab for  
28 their continuous support.  
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35 **Contributors:** LD contributed to study design, data collection, analysis and drafting and revising  
36 the manuscript. NKM contributed to analysis and revising the manuscript. AAB contributed to  
37 data collection and revising the manuscript. JLG contributed to study design, data collection,  
38 analysis and revising the manuscript. All authors approved the final version of the manuscript.  
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55 **Competing interests:** None declared  
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3 **Data availability statement:** The data (transcripts and audios files) for this study cannot be  
4  
5 made available to the public due to ethical reasons. However, the original data is reflected in the  
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7 results which provide a rich and thick description of the contents of the interviews through  
8  
9 quotations.  
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### 11 12 13 **Ethics Statement**

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16 This study was conducted between November 2019 and February 2020 and approved by the  
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18 Research Ethics Board of the University of Regina (REB# 2019-137). All women with infertility  
19  
20 provided written informed consent and received a \$10 gift card. Mental health professionals  
21  
22 provided oral consent over the phone and did not receive compensation. All participants gave  
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24 consent to be audio recorded.  
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**Table 1.** Example questions from the semi-structured interview guides

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<b>Women with Infertility</b>
What are the daily emotional challenges that you face as you have struggled to conceive?
Throughout the whole process, when have things been the hardest for you?
What have your interactions with the medical community been like throughout your fertility struggles?
What have your interactions with your family and friends been like throughout your fertility struggles?

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<b>Mental health professionals</b>
In your experience, what are the most common/specific challenges or symptoms that women present with and seek help for?
In your practice, what techniques or therapeutic approaches have you found to be most helpful in helping women struggling with infertility?

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**Table 2.** Participant characteristics.

	Frequency	% or Mean (SD)
<b>Age (years)</b>		
25-30	4	19
31-35	7	33
36-40	6	28
>41	2	10
Not reported	2	10
<b>Education</b>		
University degree	15	71
High School Diploma	5	24
Not reported	1	5
<b>Marital status</b>		
Married	17	81
Single but cohabiting	2	10
Single/never married	1	5
Not reported	1	5
<b>Combined household income (CAD)</b>		
113 000 and greater	16	76
90 -112 999	2	9
70 – 89 999	1	5
35 – 49 999	1	5
Not reported	1	5
<b>Ethnicity</b>		
Caucasian	21	100
<b>Pregnancies carried full-term</b>		
0	11	52
1	6	28
2	2	10
3	1	5
Not reported	1	5
<b>Currently trying to conceive</b>		
Yes	12	57
No	9	43
<b>Current time trying (mean, SD)</b>		
Months	23.83	23.8 (22.1)
<b>Have pursued fertility treatments</b>		
Yes	18	86
No	3	14

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**Figure 1.** Model of infertility-related distress from identified themes and sub-themes/clinical targets

For peer review only

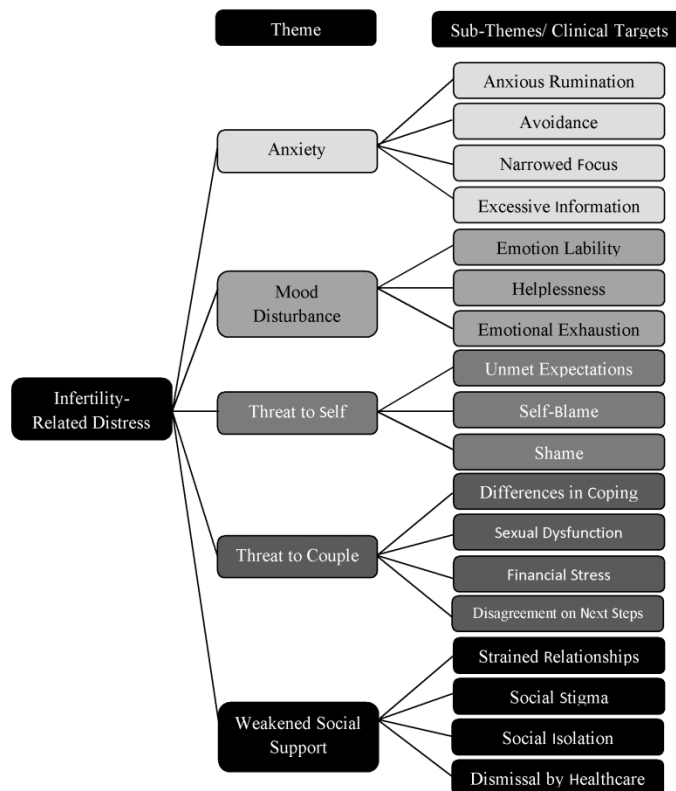


Figure 1. Model of infertility-related distress from identified themes and sub-themes/clinical targets

215x279mm (300 x 300 DPI)



**Completed COREQ Checklist**

	Item	Description
<b>Domain 1: Research team and reflexivity</b>		
<i>Personal characteristics</i>		
1.	Interviewer/facilitator	The first & second author conducted the interviews
2.	Credentials	PhD
3.	Occupation	Research fellow and Associate professor
4.	Gender	Females
5.	Experience and training	PhD researchers
<i>Relationship with participants</i>		
6.	Relationship established	For this study, there was no relationship between the participants and the researchers before the commencement of the study.
7.	Participant knowledge of the interviewer	The participants were informed that the researchers were doing the research in order to identify the unique psychological challenges that they face, and that the findings will assist in the development of a treatment manual tailored for infertility distress.
8.	Interviewer characteristics	The interviewers are both PhD researchers with social work (1 <sup>st</sup> author) and clinical psychologist (4 <sup>th</sup> author) backgrounds.
<b>Domain 2: Study design</b>		
<i>Theoretical Framework</i>		
9.	Methodological orientation and Theory	Our study is a qualitative study (Page 5). This study employed a qualitative approach using semi-structured interviews to explore the experiences of women and mental health participants. In a qualitative approach, the aim is to provide an in-depth socio-contextual and detailed description and interpretation of the topic of the research topic.
<i>Participant selection</i>		
10.	Sampling	Purposive and snowball sampling strategies were used to recruit both women and mental health professionals (MHP) (see page 5).
11.	Method of approach	To recruit women, flyers were posted in a local fertility clinic and an advertisement was posted on the Facebook page of a local infertility support group. (see page 6)

		Eligible mental health professionals were identified via a broad internet search of clinicians affiliated with or endorsed by an infertility clinic, and clinicians in private practice advertising a specialization in infertility. Those identified through the search were invited via email to participate. (see page 6)
12.	Sample size	<p>Women =21: Data saturation was achieved after the 21<sup>st</sup> interview and data collection was stopped (page 8)</p> <p>MHP = 14: Fourteen consented to participate in the study and completed the telephone interview. Eight mental health professionals were registered psychologists (4 PhD and 4 Masters), 3 were registered psychotherapists (1 PhD and 2 Masters), and 3 were registered social workers (Masters). (Page 8).</p>
13.	Nonparticipation	N/A
<i>Setting</i>		
14.	Setting of data collection	Face to face interviews and focus group discussions were conducted at the research site at the University of Regina. Other interviews were conducted over the phone. Page 6.
15.	Presence of non-participants	N/A
16.	Description of sample	See Table 2: Demographic characteristics of women participants. (Page 32)
<i>Data collection</i>		
17.	Interview guide	<p>Data was collected using two semi-structured interview guides (one for women and one for mental health professionals). The first interviews were pilot tests in order to refine the interview guides and the data was included in the analysis. (Page 6).</p> <p>Refer to Table 1 for examples of questions (Page 31).</p>
18.	Repeat interviews	N/A
19.	Audio/ visual recording	Audio recording: All participants gave consent to be audio recorded. (Page 7 and 30)
20.	Field notes	The researchers took field notes (page 7).

21.	Duration	The length of each interview ranged from 30 minutes to 100 minutes, with an average of 60 minutes. (Page 7).
22.	Data saturation	After 21 women had been interviewed, data saturation was achieved, and data collection was stopped. (see page 8).
23.	Transcripts returned	Transcripts were not returned to participants, but accuracy of information was done by paraphrasing and summarizing during interviews (page 7).
<b>Domain 3: Analysis and findings</b>		
<i>Data analysis</i>		
24.	Number of data coders	Preliminary data analysis was concurrent with data collection and was conducted independently by LD and NNM. This analysis provided a means of determining data saturation through consensus from both authors. The main data analysis was conducted independently by two authors, LD and NNM. JLG acted as an auditor of the data (see page 7).
25.	Description of the coding tree	We provided Figure 1 with categories and themes.
26.	Derivation of themes	We used thematic analysis and themes were identified from the data (see page 9).
27.	Software	We used NVivo Software, see page 8.
28.	Participant checking	Member checking was achieved by paraphrasing and summarizing the participant's contributions during focus groups and interviews. (page 7).
<i>Reporting</i>		
29.	Quotations presented	Yes, pages 10-23.
30.	Data and findings consistent	Yes, pages 10-23
31.	Clarity of major themes	Yes, page 10-23.
32.	Clarity of minor themes	N/A

# BMJ Open

## Infertility distress and clinical targets for psychotherapy: A qualitative study

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<b>Primary Subject Heading</b>:	Mental health
Secondary Subject Heading:	Reproductive medicine, Qualitative research, Mental health
Keywords:	MENTAL HEALTH, QUALITATIVE RESEARCH, Reproductive medicine < GYNAECOLOGY

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## Infertility distress and clinical targets for psychotherapy: A qualitative study

Loveness Dube<sup>1</sup>, PhD,  
Nokuthula Nkosi-Mafutha<sup>2</sup>, PhD,  
Ashley A. Balsom<sup>1</sup>, M.A.,  
Jennifer L. Gordon<sup>1</sup>, PhD\*

### Authors' Affiliation:

<sup>1</sup>Department of Psychology, University of Regina, Regina, Saskatchewan, Canada.

<sup>2</sup>Department of Nursing Education, University of the Witwatersrand, Johannesburg, South Africa

**ORCID IDs:** Loveness Dube: 0000-0002-0446-0608; Nokuthula Nkosi-Mafutha: 0000-0002-3227-1775; Ashley Balsom: 0000-0002-1795-8093; Jennifer Gordon: 000-0001-6401-6827

**\*Corresponding author at:** Department of Psychology, University of Regina, 3737 Wascana Pkwy, Regina, SK S4S 0A2, Regina, Saskatchewan, Canada. Email: [jennifer.gordon@uregina.ca](mailto:jennifer.gordon@uregina.ca)

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## Abstract

**Objectives:** An estimated 30-40% of women attending infertility tertiary care facilities experience clinically significant depression and anxiety. However, current psychological interventions for infertility are only modestly effective in this population. In this study, we aimed to identify the specific psychological components of infertility-related distress to assist in the development of a more targeted and effective therapeutic intervention. To our knowledge, this study is the first of its kind to include the views and opinions of mental health professionals who specialise in the field of infertility and the first to explore therapies currently used by mental health professionals.

**Design:** A qualitative approach using semi-structured individual interviews and focus group interviews with women who have experience with infertility and also mental health professions specializing in the field of infertility. Thematic analysis was used to identify patterns and themes emerging from the data.

**Participants:** Twenty-one women (aged 25-41 years) struggling to conceive for  $\geq 12$  months and 14 mental health professionals participated in semi-structured interviews about the psychological challenges related to infertility.

**Results:** Five themes, each divided into subthemes, emerged from the data and these were developed into a model of infertility-related distress. These five themes are: (1) anxiety, (2) mood disturbance, (3) threat to self-esteem, identity and purpose, (4) deterioration of the couple, and (5) weakened support network. In addition, therapeutic techniques used by mental health professionals were identified.

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3 **Conclusions:** The results of this study suggest specific clinical targets that future interventions  
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5 treating infertility-related distress should address.  
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8 **Key words:** Mental health; Qualitative research; Reproductive medicine.  
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For peer review only



### Strengths and limitations of this study

- The study adopted a patient-oriented approach and included interviews with mental health professionals specializing in infertility.
- The qualitative approach provided an in-depth socio-contextual and detailed description and interpretation of the experiences of the infertile women.
- The different data collection methods (interviews and focus groups) with two different sources of data (women and mental health professionals) enriched the available data.
- All participants were in heterosexual relationships, perhaps preventing the discovery of themes specific to same-sex couples.

## INTRODUCTION

Globally, 15% of couples are affected by infertility [1, 2], typically defined by the failure to achieve a clinical pregnancy after 12 months or more of regular unprotected sexual intercourse [3]. While male and female factor infertility are roughly equivalent in prevalence [4], it is well documented that women generally bear the brunt of infertility-related burden, both physically and mentally, regardless of the cause [5, 6]. In fact, research suggests that an estimated 30-40% of women attending infertility tertiary care facilities experience clinically significant depression and anxiety [7-10] and the rates are equally high in non-treatment seeking infertile women [11]. At least half of infertile women have described infertility as the most upsetting event of their lives and their distress has been found to be comparable to that of people with other chronic diseases like cancer [12]. Infertile women also reported feelings of shame, self-blame, grief, loss, anger, sadness, and lack of femininity [13, 14].

Despite the high rates of distress in this population, one meta-analysis suggests that current psychological interventions – most of which are merely modified versions of existing therapeutic approaches targeting general depression and anxiety – are only modestly effective in this population [15]. Though they were found to result in small reductions in anxiety, they were not found to improve depressive symptoms, infertility distress or marital functioning when adjusting for publication bias. Furthermore, the overall effect size associated with randomized controlled trials of psychological interventions on combined psychological outcomes was non-significant and efficacy was not found to differ according to intervention type. There is therefore a great need to develop a new psychological intervention that is more effective in reducing infertility-related distress. We propose to do so by starting with a careful look at the specific clinical targets that an infertility-specific intervention should address. The purpose of the current

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3 study was, therefore, to identify the unique psychological challenges faced by women struggling  
4 with infertility as well as identify other psychotherapeutic approaches that have yet to be used in  
5 the treatment of infertility-related distress. We therefore aimed to interview both women  
6 themselves and mental health professionals that specialize in treating this population. An  
7 inductive approach was then taken to identify the major themes and sub-themes characterizing  
8 infertility-related distress as well as to identify the major therapeutic approaches used by mental  
9 health professionals in treating this condition. To our knowledge, this study is the first of its kind  
10 to explore the unique psychological challenges faced by women struggling with infertility  
11 through the eyes of the mental health professionals who specialise in this field. Furthermore, it is  
12 the first to explore the current therapies applied by mental health professionals in treating  
13 infertility-related distress.

## 28 **METHODS**

### 31 **Study design**

34 This study employed a qualitative approach using semi-structured interviews to explore  
35 the experiences of women and mental health professionals. The qualitative approach was chosen  
36 with the aim of providing in-depth socio-contextual, detailed description and interpretation of the  
37 psychological challenges faced by infertile women [16].

### 44 **Patient and public involvement**

47 A panel of six women who were not study participants and who had experience with  
48 infertility collaborated with the researchers at two stages in this research. First, at the  
49 development of semi-structured interview guides and second, during the final stages of data  
50 analysis in the naming of the themes and sub-themes.

## Participants and sampling

The target population included 1) women who were experiencing either primary or secondary infertility and 2) mental health professionals specializing in the field of infertility. Purposive and snowball sampling strategies were used to recruit both women and mental health professionals [17]. To recruit women, flyers were posted in a local fertility clinic and an advertisement was posted on the Facebook page of a local infertility support group. Eligible participants were 18 years or older and had personal experience with infertility.

Eligible mental health professionals included Masters and PhD-level clinical psychologists, counseling psychologists, and social workers throughout Canada and the United States of America who had a self-reported specialization in infertility. Eligible mental health professionals were identified via a broad internet search of clinicians affiliated with or endorsed by an infertility clinic, and clinicians in private practice advertising a specialization in infertility. Those identified through the search were invited via email to participate.

## Setting

Face to face interviews and focus group discussions were conducted at the research site at the University of Regina. Other interviews were conducted over the phone.

## Data collection

Data was collected using two semi-structured interview guides (one for women and one for mental health professionals). The first interviews were pilot tests in order to refine the interview guides and the data were included in the analysis. Table 1 shows an example of questions included in both interview guides. Demographic information was collected via an online survey in Qualtrics (Qualtrics Inc., 2019) [18] for women with infertility and at the start of

**Table 1.** Example questions from the semi-structured interview guides

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**Women with Infertility**


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What are the daily emotional challenges that you face as you have struggled to conceive?

Throughout the whole process, when have things been the hardest for you?

What have your interactions with the medical community been like throughout your fertility struggles?

What have your interactions with your family and friends been like throughout your fertility struggles?

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**Mental health professionals**


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In your experience, what are the most common/specific challenges or symptoms that women present with and seek help for?

In your practice, what techniques or therapeutic approaches have you found to be most helpful in helping women struggling with infertility?

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the phone interview for mental health professionals. Focus group discussions for women participants were chosen as a preferred method of data collection as they encourage participants to explore topics that are seldom discussed [19], though the option of an individual interview was provided for those preferring to maintain privacy. Telephone interviews were conducted only when face-to-face interviews were not logistically possible. All mental health professional interviews were conducted by phone. Data for both women and mental health professionals was collected until saturation was achieved (i.e. new information was no longer generated).

Focus group interviews lasted 2 hours and individual interviews (face-to-face and telephone) lasted between 40 and 60 minutes. Two moderators were present during focus group interviews, one facilitating the discussion, and the other as an observer and note taker. LD

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3 conducted all individual interviews with women. The length of each professional interview  
4 ranged from 30 to 100 minutes, with an average of 60 minutes. Member checking was achieved  
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6 by paraphrasing and summarizing the participant's contributions during focus groups and  
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8 interviews. The researchers took field notes, and all interviews were audio recorded and  
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10 transcribed for thematic analysis.  
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### 14 15 **Data analysis**

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18 We followed the Consolidated criteria for reporting qualitative studies (COREQ) to  
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20 comprehensively report on important features of a qualitative study [20]. Preliminary data  
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22 analysis was concurrent with data collection and was conducted independently by LD and NNM.  
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24 This analysis provided a means of determining data saturation through consensus from both  
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26 authors. The main data analysis was conducted independently by two authors, LD and NNM.  
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28 JLG acted as an auditor of the data. Interview transcripts for women and for mental health  
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30 professionals were analysed separately before comparing the emerging themes from the two  
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32 groups. Disagreements in the analysis process were discussed and resolved by consensus. We  
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34 adapted the phases of theme development as described by Vaismoradi (2016) to enable us to do a  
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36 thematic analysis that also resonates well with the steps of qualitative content analysis [16]. The  
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38 thematic analysis was conducted in 4 phases, including initialization (reading transcriptions and  
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40 highlighting meaning units, coding and looking for abstractions in participants' accounts, writing  
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42 reflective notes, classifying and comparing), construction (labelling, translating and  
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44 transliterating, defining and describing, immersion and distancing), rectifying (relating themes to  
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46 established knowledge, stabilizing), and finalization (developing the storyline) [16]. Final  
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48 decisions about the naming of themes and subthemes were made in collaboration with the panel  
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50 of women who had helped prepare the interview guides, mentioned above. Although we used  
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3 different data sources (women and professionals) and data collection techniques (individual  
4 versus focus group interview), we compared the themes emanating from the two data sources. As  
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6 the same themes related to both participants groups' experiences emerged in the analysis, it was  
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8 decided that the results from both data sources and data collection methods would be merged,  
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10 where applicable. NVivo (NVivo 12) software was used to facilitate data management, coding  
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12 and analysis (QSR International Pty Ltd., 2019) [21].  
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## 16 17 18 **RESULTS**

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21 Thirty-three women responded and met eligibility criteria. Two focus groups of 4  
22 participants each, 7 individual face-to-face interviews, and 6 individual telephone interviews  
23 were conducted. After 21 women had been interviewed, data saturation was achieved, and data  
24 collection was stopped. Table 2 shows the demographic characteristics of the women  
25 participants.  
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33 Of the 121 mental health professionals contacted, 16 responded. Fourteen consented to  
34 participate in the study and completed the telephone interview. Eight participants were registered  
35 psychologists (4 PhD and 4 Masters), three were registered psychotherapists (1 PhD and 2  
36 Masters), and three were registered social workers (Masters). All mental health professionals  
37 were women and most practitioners worked in private practice. All had at least two years of  
38 experience, while 75% had at least five years of experience.  
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### 46 47 **Psychological experiences of women**

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50 Although data were analyzed separately for women and health professionals, the themes  
51 and subthemes emerging from both groups relating to the psychological experiences of women  
52 proved to be very similar and are presented together. Findings from this study illuminated five  
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**Table 2.** Participant characteristics.

	Frequency	% or Mean (SD)
<b>Age (years)</b>		
25-30	4	19
31-35	7	33
36-40	6	28
>41	2	10
Not reported	2	10
<b>Education</b>		
University degree	15	71
High School Diploma	5	24
Not reported	1	5
<b>Marital status</b>		
Married	17	81
Single but cohabiting	2	10
Single/never married	1	5
Not reported	1	5
<b>Combined household income (CAD)</b>		
113 000 and greater	16	76
90 -112 999	2	9
70 – 89 999	1	5
35 – 49 999	1	5
Not reported	1	5
<b>Ethnicity</b>		
Caucasian	21	100
<b>Pregnancies carried full-term</b>		
0	11	52
1	6	28
2	2	10
3	1	5
Not reported	1	5
<b>Currently trying to conceive</b>		
Yes	12	57
No	9	43
<b>Current time trying (mean, SD)</b>		
Months	23.83	23.8 (22.1)
<b>Have pursued fertility treatments</b>		
Yes	18	86
No	3	14



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3 important themes for the psychological experiences of women, which were developed into a  
4 model of infertility-related distress. These five themes are: (1) anxiety, (2) mood disturbance, (3)  
5 threat to self-esteem, identity and purpose, (4) deterioration of the couple, and (5) weakened  
6 support network (Figure 1). In the following section, themes will be discussed in detail, with  
7 supporting quotations provided from different participants, referenced with the following  
8 abbreviations where needed: individual interview (II), focus group (FG) and mental health  
9 professional (MHP).  
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## 20 **1. Anxiety**

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22 Anxiety was perhaps the most highly endorsed aspect of infertility-related distress. Both  
23 the mental health professionals and women described relentless anxiety manifesting itself  
24 through multiple behaviors, described below, aimed at seeking reassurance and avoiding further  
25 distress.  
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32 **1.1. Anxious rumination.** Women with infertility reported anxiously thinking about their  
33 infertility, often to the point of “obsession”. Both the women and mental health professionals  
34 described women’s incessant thoughts about the causes and treatment of their infertility and  
35 monitoring of their menstrual cycle and symptoms that might indicate pregnancy, to be all  
36 consuming. One woman reflected: “I was developing a lot of anxiety and spending so much time  
37 hovering about this like it was just becoming completely all consuming”. (FG) One health  
38 professional considered anxiety to be the most prominent feature of infertility-related distress:  
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48 One of the primary emotional symptoms is anxiety... rumination over the uncertainty,  
49 and anxiety sometimes about the medical procedures, anxiety related to going to the  
50 fertility clinic... Anxiety related to just not knowing. (MHP)  
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3 **1.2 Avoidance of fertility reminders.** Many women reported feeling the need to avoid  
4 activities and social events that would expose them to reminders of others' fertility, such as  
5 family gatherings where pregnant women, children, and babies would be present. Women also  
6 described avoiding social media to avoid seeing pregnant persons and birth announcements:  
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12 And then all of a sudden, birth announcements...pregnancy announcements start to  
13 bother you... You don't want to go on your social media because you just don't want to  
14 see everybody having fun with their babies and their families and getting pregnant...and  
15 you just feel like you're left behind. (II)  
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21 Mental health professionals also reported this avoidance as a frequently observation.  
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23 "Everything and everyone can be very triggering", said one. Both women and professionals  
24 linked this avoidance of potentially triggering social situations with a gradual increase in social  
25 isolation and distancing from once-close friends and family members.  
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31 **1.3. Narrowed focus on fertility related activities.** It was mostly mental health  
32 professionals who made observations related to this sub-theme by mentioning that, over time,  
33 women would increasingly focus on their attempts to conceive at the cost of their previously  
34 enjoyed activities. Events and plans would be put on hold for the sake of their treatments or 'in  
35 case' they became pregnant. The professionals also explained that, over time, getting pregnant  
36 often became the topic of every conversation within a couple and all actions and activities were  
37 solely focused on conceiving and the next steps in the process:  
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48 Fertility treatment becomes everything, it consumes their everyday life...A tendency for  
49 couples going through fertility [treatments] or struggling with infertility is that that's all  
50 they talk about, fertility and next steps. (MHP)  
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3 Relatedly, one woman explained that the scheduling of fertility treatments often made it  
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5 difficult to plan:  
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8 I hate that I can't plan stuff because we are still doing IVF [in-vitro fertilization], we  
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10 have embryos that are still on ice. And so, every try is three months apart and we love to  
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12 travel but it's like you can't book because you don't know when exactly that next  
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14 treatment is.... It's just that lack of being able to plan. (FG)  
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18 **1.4. Excessive information seeking.** Spending an excessive amount of time seeking  
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20 information about the causes and potential treatment of infertility, usually via the internet, was  
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22 described by both women and mental health professionals: “Sometimes I do see... pure  
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24 obsession, it can actually look like where the person is frantically researching online repeatedly  
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26 for explanation as to why they haven't gotten pregnant.” (MHP) Health professionals also voiced  
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28 concerns that this constant searching for answers was potentially harmful for women as the  
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30 information they obtained was often of questionable validity.  
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35 **1.5. Summary.** Every woman and health professional interviewed emphasized elements  
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37 of anxiety related to infertility. Women who had undergone fertility treatments related their  
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39 anxious rumination to the success of the many procedures involved in the treatment process  
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41 while women who had only struggled to conceive without medical intervention reported being  
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43 very focused on the different phases of their menstrual cycle, identifying signs of fertility, and  
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45 looking for signs that a cycle was positive. This excessive mental energy devoted to all things  
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47 infertility, coupled with a desire to avoid witnessing evidence that others are conceiving without  
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49 difficulty, resulted in a decreased engagement in previously enjoyed activities and an increase in  
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51 social withdrawal. Anxiety as a theme was more prominent in focus groups and face-to-face  
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53 interviews when compared to interviews conducted over the phone. We hypothesize that perhaps  
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3 researchers were better able to build rapport in face-to-face interactions, allowing women to feel  
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5 more comfortable sharing their challenges.  
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## 8 **2. Mood disturbance**

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11 This theme captured women's experience of enormous fluctuations between positive and  
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13 negative emotion, eventually leading to complete exhaustion and, in some cases, depression.  
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17 **2.1. Emotional lability.** As common as the confirmation of anxiety was the description  
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19 of infertility as an “emotional rollercoaster”: at the start of each cycle, hope and excitement  
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21 would build, only to be met with extreme disappointment and grief following each negative test  
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23 or miscarriage:  
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26 Every month, you go through this cycle of excitement or hope and then followed by no  
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28 success... You get depressed, you get very discouraged or very down...and then you  
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30 think, ‘Oh, I'm not going to invest any more energy’, but then just by nature, you do. And  
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32 then you get hopeful and excited again, and you just go through this rollercoaster of  
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34 emotions that way. (II)  
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38 Women who had undergone fertility treatments explained that their mood was highly  
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40 dependent on the outcomes of each step in fertility treatments: ultrasounds, egg retrieval, and  
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42 embryo transfer. Some women also reported that the hormones taken for infertility exacerbated  
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44 their emotional lability: “The hormones that they have you on wreak havoc with my entire being,  
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46 I felt crazy.” (FG2) Other women reported being overly sensitive or irritable in their daily lives  
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48 because of their high stress levels, directly related to their struggles to conceive.  
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53 **2.2. Helplessness.** Several women stated that one of the biggest challenges related to  
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55 infertility was the feeling of being completely helpless in the process of trying to conceive.  
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3 Women reported feeling extremely frustrated by their lack of control over the outcome of any  
4 given cycle. One woman participating in a focus group lamented: “One of the hardest aspects is  
5 the helplessness that I feel...because most of the things in my life - it's like okay, you do A B C  
6 D and you get this outcome but with this there's just no guarantees.”  
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13 One participant explained that the sense of a lack of control over the process led her to  
14 even contemplate not taking her medication so that she could at least have “some sense of  
15 control over destiny”. Women also expressed frustration at the lack of information and choice  
16 regarding their treatment options: “I feel like they have a very set order [in fertility clinics but]  
17 they are not going to tell you why this is the order in which they do things.” (FG) Mental health  
18 professionals similarly remarked that women were given little opportunity to determine the  
19 course of their treatment in medical settings.  
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30 **2.3. Emotional exhaustion.** Women participants reported that the constant alternation  
31 between hope and despair, along with their feelings of helplessness, led them to become  
32 emotionally drained. One woman explained that fertility treatments had drained her to the point  
33 of requiring a mental health break from work: “I went to the doctor and I said to her, ‘I need to  
34 get off work, I need to be on stress leave because I can't do this anymore.’” (II) Another woman  
35 recalled a time when she had “hit rock bottom” and became suicidal because of her difficulties  
36 conceiving.  
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46 **2.4. Summary.** Nearly all women reported that their mood dipped at certain points  
47 throughout their cycle each month, particularly after a negative outcome. Feelings of complete  
48 helplessness over the process and outcome of each cycle was also very prominent. A smaller  
49 subset of women, however, related the constant up and down from hope to despair to the  
50 development of emotional exhaustion and what sounds like clinical depression.  
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### 3. Threat to self-esteem, identity and purpose

This subtheme captured women's reports that infertility had contributed to a questioning of their identity and negative internal dialogue about their worth and the worth of their life in the absence of motherhood.

**3.1. Unmet expectations for self and one's future.** Many of the women reported an enormous sense of loss as they reflected on their childhood dreams of being a mother. One woman remembered:

When I was a kid, I wasn't dreaming about being a doctor or vet or thinking about the perfect wedding, I was thinking about being a mom. And it was just a sense that the vision of what I had for my future wasn't possible. (FG)

Mental health professionals added that for many women, motherhood was so closely tied to their identity as a woman that their infertility diagnosis threatened their very sense of who they were as a person:

The number one thing that I see and can identify hands down is there is an attack on their identity and their sense of self, the narrative that they believed about who they were, what their reproductive story was, and they feel very shattered from that because this story is not playing out. (MHP)

Health professionals also reported that women having to pursue third-party reproduction also grieve the loss of pregnancy in the case of surrogacy, and the loss of genetic connection to their child in the case of egg donation.

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**3.2. Self-blame.** Several women reported believing that they were partly to blame for their infertility, particularly among women with female factor infertility: “You have to deal with the mental aspect of knowing...that I was the reason that we didn’t have kids... If [my husband] was with someone else, he could be having those kids.” (II) Women also reported that they tended to question whether any of their behaviors might be contributing to their diagnosis or a failed cycle. One woman, a long-distance runner, recalled: “A few of my IUIs [intrauterine inseminations] were right after doing a very long race and so I felt like maybe that’s why it didn’t work. I was blaming myself that it didn’t work.” (FG) Mental health professionals corroborated these reports.

**3.3. Shame.** Many women reported feeling ashamed of their diagnosis of infertility, seeing themselves as “broken”, leading them to keep their struggles a secret or to share with only a few close others: “If I had cancer, it would have been open, and we could have talked about it and my community would have supported me. But when it's infertility, you feel different, isolated, and embarrassed, and ashamed” (II). Mental health professionals echoed the same sentiment, highlighting the difference between how infertility was perceived compared to other medical conditions.

**3.4. Summary.** Within this theme, we see that infertility often triggers an existential crisis of sorts: a profound questioning of what it means to be a woman in the absence of fertility and the potential for motherhood. Women were left wondering what their lives would look like and what value it might have if motherhood was never achieved. This seems to be particularly the case for women who reported having wanted to be a mother since childhood.

#### 4. Deterioration of the couple

As one mental health professional reported, some relationships were strengthened by the process of struggling to conceive while others suffered to the point of divorce. The following challenges, however, appeared to be common even among couples whose relationship was strengthened overall.

**4.1. Partner differences in coping.** Women described their frustration related to differences in coping between themselves and their partners. It appears that women often took a more active role and expressed their emotions more openly than their partners, leading them to perceive their partners as being less emotionally invested in the goal of conceiving:

It makes me feel like I'm the one that's always worrying and stressing and thinking about things and making appointments and tracking my cycle and kind of carrying the burden in a way...He's just kind of very laid-back about the situation...it gets a little frustrating for me. (II)

Another woman reflected on her and her husband's different ways of coping with grief following a miscarriage:

The first time the miscarriage happened, my husband kind of grieved separately because he didn't want to grieve in front of me because he thought that it wouldn't help how I was doing with it...so I just thought like, 'Hey, we had a miscarriage, and he's fine.' (II)

Mental health professionals agreed that many challenges within the couple related to partners not 'processing' events surrounding infertility at the same pace.



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3 **4.2. Negative impact on couple's sex life.** Women commonly reported a deterioration of  
4 the couple's sex life because, over time, the purpose of sex became solely to achieve conception  
5 rather than intimacy or enjoyment: "it just seems like work" (II). One mental health professional  
6 described sex as becoming "transactional" in nature and reported that women often found it  
7 difficult to engage without thinking about the goal of conceiving.  
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15 **4.3. Stress related to financial burden of fertility treatments.** Given the high costs of  
16 fertility treatments, for the most part not covered by medical insurance, women reported that  
17 strained finances became a prominent topic of conversation among couples pursuing assisted  
18 reproductive technologies:  
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25 Conversations around the cost of everything just because that puts a lot of strain on our  
26 relationship...How can we afford it?...How can we make it work? We don't really have  
27 time to wait and save up for this, we just have to figure it out now. (FG)  
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33 Concerns about finances would also lead to stressful discussions around the feasibility of  
34 continuing treatment. The same sentiment was echoed by the mental health professionals who  
35 described the financial strain brought on by fertility treatments as being a challenge for most  
36 couples.  
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43 **4.4. Couple disagreements on next steps.** A few women reported that tension within  
44 the couple arose due to differences in opinion about next steps to take in trying to conceive: "I  
45 got divorced because... I think he was done before I was, he just didn't want to do it anymore."  
46 (FG). One woman recalled that she and her husband went into a doctor's appointment with very  
47 different intentions and expectations, which led to conflict afterwards:  
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3 “I went in thinking like, ‘Okay, we're going to get the information and move forward.’

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5 He went in thinking, ‘Okay, I'm going in to get the information and then make a decision  
6  
7 on that.’ So, we were on different pages going in.” (II)

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10 **4.5. Summary.** While a few women reported that their relationships were strengthened  
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12 overall because of going through the challenges of infertility together, all women referred to  
13  
14 some difficulties within the couple at one time or another. A subset of women reported that their  
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16 relationship had been severely tested (or severed) by their struggles with infertility and these  
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18 serious conflicts seemed to be primarily related to differences in opinion regarding next steps to  
19  
20 take regarding treatment.  
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## 24 25 **5. Weakened social support network**

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28 The theme of weakened social support networks highlights women participants’ struggles  
29  
30 with their loved ones due to stigma and lack of education surrounding infertility. Women also  
31  
32 reported that their experiences were often dismissed by health service providers.  
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36 **5.1. Strained relationships with friends and family.** Women explained that  
37  
38 relationships with friends and family were often strained in the context of infertility, in part due  
39  
40 to the barrage of unhelpful comments and questions they received from well-meaning loved  
41  
42 ones. One woman explained why she felt that she couldn’t open up to her friends about her  
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44 infertility:  
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48 I have a lot of friends who mean well, and they just keep saying it'll happen...I just don't  
49  
50 know what they want me to say to that... I feel like if I talk to them about it, they're just  
51  
52 gonna be like, ‘Oh just stay positive’. (FG)  
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3 Several women reported that their family members often showed a lack of understanding  
4 about the emotional pain they were experiencing, even when they were open with them about the  
5 challenges they were facing: “All my mom said was that I was a b\*\*\*\* that Christmas. And so,  
6 there was just no understanding.” (FG) Participants also struggled with feelings of envy,  
7 jealousy, and resentment towards friends or family who had conceived easily, which also  
8 contributed to distance with once-close loved ones:  
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17 The relationship with my brother is still pretty strained. Him and his wife actually ended  
18 up getting pregnant five weeks before I did, and they only tried for a couple of days...  
19 and then got pregnant right away. ...I felt like they didn't deserve their pregnancy  
20 because they didn't have to work for it. (II)  
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27 **5.2. Social stigma.** Women reported that they perceived a great amount of social stigma  
28 related to infertility, which created anxiety around discussing it openly: “I felt reluctant to tell  
29 friends and other people. And I still haven't told everyone in my life...just because I didn't want  
30 to be an object of pity, I didn't want anyone to think I was a barren woman.” (II). Other women  
31 refrained from telling others about their infertility because they did not want to be judged by  
32 friends and family who might comment on the woman's potential role in contributing to her  
33 problems conceiving.  
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44 **5.3. Social isolation.** An increase in social isolation seemed to be a consequence of  
45 several processes – women's avoidance of fertility reminders (from theme 1), their attempts to  
46 avoid unhelpful comments and questions from others, and the pressure to hide their  
47 preoccupation with their infertility: “I feel like it kind of closed off some of my opportunities for  
48 healthy, normal socialization...and I think to some extent, that's impeded my ability to form  
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3 closer relationships with people too.” (II) For example, one participant recounted avoiding get-  
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6 togethers at bars or pubs in order to avoid questions about why she wasn’t drinking alcohol:

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8 One of the things I find really difficult about trying to conceive is you can't just go for a  
9  
10 casual night out with friends and have drinks... I have tried going out and just drinking  
11  
12 non-alcoholic drinks, but inevitably, someone tries to order another round or says, ‘Why  
13  
14 don't you want to do this?’ (II)  
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18 Another participant recalled missing out on a family get-together because a family  
19  
20 member announced that she was pregnant at the event and she didn’t want to show her family  
21  
22 how upset she was: “I so distinctly remember sitting in my bedroom and just crying... I knew I  
23  
24 couldn't leave our room.” (FG)  
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28 **5.4. Feeling dismissed by health service providers.** Several participants recounted  
29  
30 feeling disappointed with the service they had received from their mental health provider. One  
31  
32 woman recounted her encounter with a mental health professional specializing in infertility:  
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36 She gave me quite a cookie cutter approach to her counseling... like, you're going  
37  
38 through infertility so you must be experiencing this and this and this. I was like ‘Oh no, I  
39  
40 am not experiencing that.’ (II)  
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43  
44 In addition, women described feeling dismissed by their reproductive healthcare service  
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46 providers who sometimes minimized the emotional pain associated with what they were  
47  
48 experiencing. One woman seeking care for a suspected miscarriage remembered:  
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52 My family doctor... He told me he didn't think I was miscarrying. He also said, ‘If you  
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54 are, then it's not really a big deal because you're young and you can keep trying. I've had  
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3 patients that have been trying for years and years and years and you really shouldn't be  
4 worried yet'. And that's really difficult and frustrating to hear. (II)  
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8 Mental health professionals echoed the same sentiments, remarking that younger women  
9 are especially prone to receiving dismissive comments from the medical community:  
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13 Women with a female factor diagnosis who are very, very young often have a very hard  
14 time in the treatment process because they're often not taken seriously...I've heard many  
15 specialists tell them, 'You have lots of time, don't worry about it, it'll happen for you',  
16 which can be really quite dismissive of their feelings and their coping. (MHP)  
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23 **5.5. Summary.** Through this theme, it became clear that women's tendency to distance  
24 themselves from others and the activities they used to enjoy was partly related to a desire to  
25 avoid having to discuss their infertility with others, whom they generally found to be unhelpful  
26 in providing emotional support. Several women perceived a lack of compassion and  
27 understanding of the emotional aspects of infertility among both mental health and reproductive  
28 health professionals, leading them to feel truly alone in coping with their emotional pain.  
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### 38 **Therapeutic techniques used by mental health professionals**

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41 All the mental health professionals reported using an eclectic approach to psychotherapy  
42 for infertility. They combined techniques from a number of different therapeutic approaches,  
43 including but not limited to the following: supportive therapy, cognitive behavioural therapy  
44 (CBT), dialectical behavioural therapy (DBT), acceptance and commitment therapy (ACT),  
45 compassion focused therapy, mindfulness, counselling, eye movement desensitization and  
46 reprocessing (EMDR), cognitive processing therapy (CPT), emotion-focused therapy (EFT),  
47 solution focused therapy, psychodynamic therapy, interpersonal psychotherapy (IPT), internal  
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3 family systems (IFS), expressive therapy, existential therapy, and upside down therapy. A short  
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5 description of these therapeutic approaches is given in Table 3.  
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For peer review only

**Table 3.** Brief description of therapeutic approaches mentioned by mental health professionals.

<b>Therapeutic approach</b>	<b>Therapeutic focus</b>
Acceptance and Commitment Therapy (ACT) [22]	Teaching mindfulness strategies to decrease avoidance and increase focus on the present.
Cognitive behavioural therapy (CBT) [23]	Changing cognitive distortions and changing behaviours to improve mental health
Cognitive processing therapy (CPT) [24]	Challenging unhelpful beliefs related to trauma.
Counselling [25]	Providing emotional support to clients experiencing crisis, typically unstructured.
Dialectical behavioural therapy (DBT) [26]	Improving emotion regulation and improving relationships. Is highly successful for borderline personality disorder.
Emotion-focused therapy (EFT) [27]	Increasing the awareness, acceptance, expression and regulation of emotion.
Existential therapy [28]	Focuses on concepts related to human existence, such as death, responsibility, and the meaning of life.
Expressive therapy [29]	Using creative arts to facilitate the exploration of difficult emotions.
Eye movement desensitization and reprocessing (EMDR) [30]	Encouraging the patient to recall a traumatic memory while simultaneously moving their eyes from side to side.
Internal family systems (IFS) [31]	Identifying and addressing the multiple “sub-personalities” or families that form a person’s identity.
Interpersonal psychotherapy (IPT) [32]	Resolving interpersonal problems and facilitating social support.
Mindfulness-based approaches [33]	Fostering greater awareness, attention, and acceptance of present moment experiences.
Psychodynamic therapy [34]	Increasing client awareness of the unconscious influences on their past and present behaviour.
Solution focused therapy [35]	Helping the client identify resources that will help them develop a realistic and sustainable solution to the problems they are facing.
Upside down therapy [36]	Incorporating elements of play to increase distance between oneself and the content of one’s thoughts.

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3 CBT, DBT, and mindfulness-based approaches stood out as the most used, although  
4 always in combination with others. Participants also reported applying CBT with caution: “At  
5 times I might reach for CBT...but really I have to be very careful because...the distress that a  
6 woman is experiencing...are a normal response to an abnormal situation.” (MHP 1) A second  
7 mental health professional echoed these concerns: “There’s nothing more invalidating to a  
8 woman who’s experienced multiple losses than when you sit down with her and would say, ...  
9 ‘So, what are the cognitive distortions?’...It’s invalidating.” (MHP 1) Other mental health  
10 professionals found that CBT was not at all useful in the context of infertility:  
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22 CBT and solution-focused [therapy] are pretty useless with this population...and I know  
23 the evidence doesn’t support that because that’s the only theory [CBT] that has any  
24 evidence-based research behind it, which creates its own bias in and of itself. (MHP 11)  
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30 Several mental health professionals reported using mindfulness techniques, particularly  
31 for addressing anxiety, with one reporting: “We do a lot of emotion regulation and mindfulness  
32 grounding and learning to breathe and settle their anxiousness.” (MHP 3) A second professional  
33 stated: “Women really find it helpful to learn just ways of the balance between accepting, and  
34 letting go, and having hope, and I think... that can be found through mindfulness.” (MHP 12)  
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Others reported combining a mindfulness approach with traditional CBT: “I often and typically  
in practice use mindfulness and CBT together.” (MHP 13) Still others endorsed using  
mindfulness in the context of other therapeutic approaches that include mindfulness as part of its  
focus, including ACT and DBT, a CBT-based approach that incorporates mindfulness and other  
skills aimed at promoting distress tolerance: “I use...DBT techniques because the amount of  
distress that I see in these women is profound.” (MHP 14)



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Several mental health professionals emphasized that flexibility was critical and that adherence to a therapeutic approach should not interfere with responding to a client's needs in any given session. One therapist explained: "Client centered is so important...some people just want to be heard and validated, and that's why they're coming to therapy." (MHP 7) Another expressed a similar sentiment: "everyone is different...looking at what are their goals... so very client-centered focus." (MHP 9)

In sum, all mental health professional participants reported using techniques from more than one psychotherapeutic approach in order to address the psychological symptoms associated with infertility and to target the specific needs of each client.

## DISCUSSION

The purpose of the current study was to gain a deeper understanding of infertility-related distress as well as gather information about which psychotherapeutic approaches were being used by mental health professionals for the treatment of infertility-related distress. The ultimate aim was to inform the development of an intervention better tailored to infertility and more effective than currently available ones. While some of the identified themes and sub-themes are common to mood and anxiety disorders unrelated to infertility, the results of the current study also highlighted several challenges that are clearly unique to infertility. Women's reports, corroborated by the accounts of mental health professionals specializing in infertility-related distress, paint a picture of infertility-related distress in which one is highly preoccupied and emotionally invested in the day-to-day occurrences of the menstrual/treatment cycle, leading to high anxiety and fluctuating mood. As they are preoccupied with their current efforts and wish to avoid having to explain themselves to others or to submit themselves to others' pregnancies and children, they become more reclusive and spend less time engaged in activities that previously

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3 enriched their lives. They worry about who they will be and what their lives will look like if they  
4 never conceive. At the same time, at home, women are struggling to connect with their partner as  
5 they do not always find themselves to be on the same page with regards to various reproductive  
6 events and/or decisions to be made. In a subset of women, these emotional struggles contribute  
7 to clinical mental health problems over time and, in some, the complete dissolution of their  
8 relationship. Below, we review each of the identified themes in greater detail and compare our  
9 findings with those of other studies.  
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20           Anxiety emerged as one of the most prominent features of infertility-related distress,  
21 consistent with previous findings from other studies in which anxious rumination was reported to  
22 be a common feature of infertility [37, 38]. A few studies have also reported on women's  
23 narrowed focus on infertility to the exclusion of other activities, as well as excessive information  
24 seeking as behavioral features of anxiety [39-41]. In this study, these subthemes were more  
25 prominent, and we suspect that the inclusion of mental health professionals, providing an  
26 outsider's perspective, was a unique feature in the current study that may have facilitated the  
27 identification of these subthemes.  
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39           With regards to the second theme, mood disturbance, other researchers have also reported  
40 on the 'emotional rollercoaster' of infertility, as well as the loss of control that women frequently  
41 experience [6, 37, 42, 43]. Emotional exhaustion and burnout have also been reported as a  
42 common feature of infertility, resulting from the chronic exposure to the emotional ups and  
43 downs of infertility [41, 44]. This finding is consistent with the high rate of clinical depression  
44 seen among women struggling with infertility [7, 9, 10]. The third theme – threat to self-esteem,  
45 identity and purpose – is somewhat similar to previous reports that women's view of themselves  
46 and their future identities are challenged by infertility, leading to feelings of role loss or role  
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3 failure and the development of a negative self-perception [6, 41, 42]. Pedro and Andipatin (2014)  
4 also reported on women's tendency to blame themselves for their infertility [45]. Finally, the  
5 broad themes of deterioration of the couple [37, 38, 43], and of weakened social support systems  
6 [42, 43] have been previously identified. However, the identification of specific sub-themes  
7 within these broader issues is unique to the current study and helps to inform the identification  
8 and development of more effective psychotherapies directly targeting infertility-related distress.  
9  
10 The sub-theme relating to negative interactions with healthcare providers adds to the findings of  
11 previous studies [46, 47] and highlights the need for increased awareness and education among  
12 healthcare providers in addressing the emotional aspect of infertility with sensitivity and  
13 compassion.  
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27 Mental health professionals reported using an array of techniques borrowed from a range  
28 of psychotherapy approaches, some more evidence-based than others, to address the unique  
29 challenges associated with infertility-related distress. CBT, arguably the psychotherapeutic  
30 approach most supported by research evidence for the treatment of depression and anxiety  
31 unrelated to infertility [23] was met with disdain by some and cautious acknowledgement of its  
32 potential benefits by others. Specific concerns about CBT related to its focus on "cognitive  
33 distortions" as being invalidating of the very natural emotions resulting from infertility.  
34 Approaches incorporating mindfulness, commonly termed "third-wave" psychotherapy  
35 approaches, were mentioned numerous times as being helpful, including, acceptance and  
36 commitment therapy, dialectical behavioural therapy, and mindfulness-based cognitive therapy,  
37 all of which are supported by growing bodies of research evidence for distress unrelated to  
38 infertility [23, 26, 48]. Other therapy approaches mentioned, such as emotion focused therapy,  
39 upside down therapy, and existential therapy, have modest to no research support as of yet [49].  
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3 These findings, in combination with recent meta-analytic evidence suggesting that the  
4 efficacy of current psychotherapeutic approaches to infertility is modest [15], perhaps reflect a  
5 need for a new psychotherapeutic approach that combines techniques from various approaches to  
6 create a more tailored intervention that addresses the unique psychological challenges identified  
7 here. While cognitive restructuring, progressive muscle relaxation, and mindfulness meditation  
8 are the most-used and tested approaches to date for the treatment of infertility-related distress,  
9 their efficacy in this population is limited [15]. Several other approaches mentioned by the  
10 mental health professionals may better target the unique aspects of infertility-related distress. For  
11 example, some of the techniques used in DBT aimed at improving distress tolerance [26] may  
12 help women cope with intense distress during medical procedures or after very upsetting news.  
13 The interpersonal effectiveness skills taught in DBT may also help individuals appropriately  
14 interact with the people in their lives who say unhelpful or upsetting things related to their  
15 infertility.  
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34 Acceptance and Commitment Therapy, mentioned by several mental health professionals  
35 in our study, may be useful in addressing the avoidance of infertility reminders, which emerged  
36 as one of the subthemes of infertility-related anxiety, as ACT encourages women to engage in  
37 activities that align with their values, in spite of the distress that doing so may cause [22]. For  
38 example, a woman who highly values being a supportive sister will be encouraged to work up to  
39 going to her sister's baby shower. Importantly, cognitive strategies and mindfulness exercises are  
40 first introduced to equip clients with the tools needed to cope with the distress they encounter  
41 through the process of exposure. To date, studies conducted in the Middle East have applied  
42 ACT to infertility-related distress with promising results [50-52], though it has yet to be tested in  
43 North America.  
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3 Several of the mental health professionals highlighted the use of mindfulness-based  
4 approaches. Although mindfulness approaches have proven to be of limited efficacy for  
5 infertility-related distress, one mindfulness-based approach that has yet to be applied to infertility  
6 is loving-kindness meditation (LKM) [53], which seems to map on well to both shame/self-  
7 blame and severed relationships with others. LKM is a Buddhist practice aimed at increasing  
8 compassion towards self and others. As a first step, one meditates while focusing on statements  
9 that promote self-love and self-compassion (e.g., ‘May I be free from mental suffering or  
10 distress’), while attempting to let go of any self-judgment or self-hatred. Next, thoughts and  
11 statements center around an elderly loved one, then a close loved one, next a neutral person, and,  
12 finally, someone with whom you have a difficult relationship or feel bitterness towards.  
13 Mounting research [54] suggests that LKM increases both positive self-regard as well as positive  
14 feelings towards others. In infertility, it may therefore be used to reduce feelings of shame  
15 related to the diagnosis while also improving relationships with others who fail to provide the  
16 emotional support that was expected or hoped for.  
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36 Interpersonal psychotherapy, which was also mentioned by several mental health  
37 professionals, may also be an effective approach to improving a woman’s interpersonal  
38 relationships within the context of infertility. IPT is a time-limited, evidence-based therapy that  
39 uses techniques such as communication analysis and role-playing to address four main  
40 interpersonal issues: interpersonal disputes, role transitions, grief, and interpersonal deficits [32,  
41 55]. Within the context of infertility, interpersonal disputes may include disagreements with  
42 one’s partner about next steps to take in fertility treatments or negative interactions with loved  
43 ones who inadvertently make unhelpful comments. ‘Role transitions’ may also be relevant for  
44 women contemplating stopping treatments and who are trying to make peace with living a child-  
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3 free life. Finally, ‘grief’ is clearly applicable to negative pregnancy test outcome or miscarriage.  
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5 To our knowledge, a single pilot study has tested IPT for infertility-related distress, with  
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7 promising results [56].  
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11       Though CBT has been applied to infertility in a number of studies, with limited results,  
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13 there are a number of CBT-based techniques that have yet to be used but that may address some  
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15 of the specific infertility-related psychological challenges raised in this study. Specifically, given  
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17 the prominence of anxious rumination and excessive information seeking, the incorporation of  
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19 ‘worry time’ may be warranted. ‘Worry time’ is a technique that is commonly used in CBT for  
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21 generalized anxiety disorder and involves having the client set aside a certain amount of time  
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23 daily (e.g., 30 minutes once or twice daily) to devote to their ongoing worries [23, 57]. In the  
24  
25 context of infertility, this time could be used to research potential treatments, budget for fertility  
26  
27 treatments, or simply contemplate what life might be like without children. Whenever an  
28  
29 infertility-related worry pops up outside of ‘worry time’, women would be encouraged to jot  
30  
31 down their concerns on a notepad, to be considered further during the next worry time. While  
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33 this technique may seem counter-intuitive, research has found it to be effective in reducing the  
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35 amount of time spent ruminating overall [23, 57].  
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42       A few limitations are worth mentioning. Our sample was relatively homogeneous, being  
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44 largely Caucasian and of high socioeconomic status, potentially limiting the generalizability of  
45  
46 our findings to the larger population. All participants were also in heterosexual relationships,  
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48 perhaps preventing the discovery of themes specific to same-sex couples. Despite these  
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50 limitations, our study is strengthened by its patient-oriented approach and its inclusion of mental  
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52 health professionals specializing in infertility.  
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3 Ultimately, it is hoped that the careful consideration of the unique aspects of infertility-  
4 related distress will result in the most effective intervention possible for this population. The  
5 findings of the current study highlight the need to address individuals' struggles with anxiety and  
6 depressive mood while also repairing fractured couple and interpersonal relationships,  
7 facilitating continued engagement in activities that enriched one's life before the diagnosis of  
8 infertility and that help to increase resilience in the face of the stressful circumstances  
9 surrounding infertility.  
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21 mental health professionals who gave their invaluable time to contribute to this study. A special  
22 thanks goes to the panel of women and the team at the Women's Mental Health Research lab for  
23 their continuous support.  
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30 **Contributors:** LD contributed to study design, data collection, analysis and drafting and revising  
31 the manuscript. NKM contributed to analysis and revising the manuscript. AAB contributed to  
32 data collection and revising the manuscript. JLG contributed to study design, data collection,  
33 analysis and revising the manuscript. All authors approved the final version of the manuscript.  
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50 **Competing interests:** None declared  
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52 **Data availability statement:** The data (transcripts and audios files) for this study cannot be  
53 made available to the public due to ethical reasons. However, the original data is reflected in the  
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3 results which provide a rich and thick description of the contents of the interviews through  
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5 quotations.  
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### 8 **Ethics Statement** 9

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11 This study was conducted between November 2019 and February 2020 and approved by the  
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13 Research Ethics Board of the University of Regina (REB# 2019-137). All women with infertility  
14  
15 provided written informed consent and received a \$10 gift card. Mental health professionals  
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17 provided oral consent over the phone and did not receive compensation. All participants gave  
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19 consent to be audio recorded.  
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**Figure 1.** Model of infertility-related distress from identified themes and sub-themes/clinical targets

For peer review only

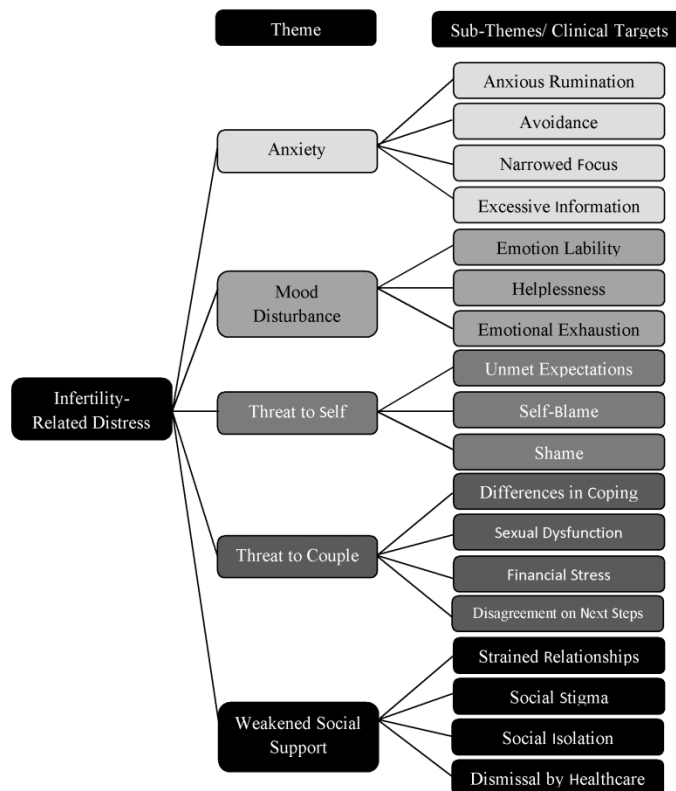


Figure 1. Model of infertility-related distress from identified themes and sub-themes/clinical targets

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**Completed COREQ Checklist**

	Item	Description
<b>Domain 1: Research team and reflexivity</b>		
<i>Personal characteristics</i>		
1.	Interviewer/facilitator	The first & second author conducted the interviews
2.	Credentials	PhD
3.	Occupation	Research fellow and Associate professor
4.	Gender	Females
5.	Experience and training	PhD researchers
<i>Relationship with participants</i>		
6.	Relationship established	For this study, there was no relationship between the participants and the researchers before the commencement of the study.
7.	Participant knowledge of the interviewer	The participants were informed that the researchers were doing the research in order to identify the unique psychological challenges that they face, and that the findings will assist in the development of a treatment manual tailored for infertility distress.
8.	Interviewer characteristics	The interviewers are both PhD researchers with social work (1 <sup>st</sup> author) and clinical psychologist (4 <sup>th</sup> author) backgrounds.
<b>Domain 2: Study design</b>		
<i>Theoretical Framework</i>		
9.	Methodological orientation and Theory	Our study is a qualitative study (Page 6). This study employed a qualitative approach using semi-structured interviews to explore the experiences of women and mental health participants. In a qualitative approach, the aim is to provide an in-depth socio-contextual and detailed description and interpretation of the topic of the research topic.
<i>Participant selection</i>		
10.	Sampling	Purposive and snowball sampling strategies were used to recruit both women and mental health professionals (MHP) (see page 7).
11.	Method of approach	To recruit women, flyers were posted in a local fertility clinic and an advertisement was posted on the Facebook page of a local infertility support group. (see page 7)

		Eligible mental health professionals were identified via a broad internet search of clinicians affiliated with or endorsed by an infertility clinic, and clinicians in private practice advertising a specialization in infertility. Those identified through the search were invited via email to participate. (see page 7)
12.	Sample size	<p>Women =21: Data saturation was achieved after the 21<sup>st</sup> interview and data collection was stopped (page 9)</p> <p>MHP = 14: Fourteen consented to participate in the study and completed the telephone interview. Eight mental health professionals were registered psychologists (4 PhD and 4 Masters), 3 were registered psychotherapists (1 PhD and 2 Masters), and 3 were registered social workers (Masters). (Page 10).</p>
13.	Nonparticipation	N/A
<i>Setting</i>		
14.	Setting of data collection	Face to face interviews and focus group discussions were conducted at the research site at the University of Regina. Other interviews were conducted over the phone. Page 7.
15.	Presence of non-participants	N/A
16.	Description of sample	See Table 2: Demographic characteristics of women participants. (Page 33)
<i>Data collection</i>		
17.	Interview guide	<p>Data was collected using two semi-structured interview guides (one for women and one for mental health professionals). The first interviews were pilot tests in order to refine the interview guides and the data was included in the analysis. (Page 7).</p> <p>Refer to Table 1 for examples of questions (Page 32).</p>
18.	Repeat interviews	N/A
19.	Audio/ visual recording	Audio recording: All participants gave consent to be audio recorded. (Page 8 and 31)
20.	Field notes	The researchers took field notes (page 8).

21.	Duration	The length of each interview ranged from 30 minutes to 100 minutes, with an average of 60 minutes. (Page 7).
22.	Data saturation	After 21 women had been interviewed, data saturation was achieved, and data collection was stopped. (see page 8).
23.	Transcripts returned	Transcripts were not returned to participants, but accuracy of information was done by paraphrasing and summarizing during interviews (page 8).
<b>Domain 3: Analysis and findings</b>		
<i>Data analysis</i>		
24.	Number of data coders	Preliminary data analysis was concurrent with data collection and was conducted independently by LD and NNM. This analysis provided a means of determining data saturation through consensus from both authors. The main data analysis was conducted independently by two authors, LD and NNM. JLG acted as an auditor of the data (see page 8).
25.	Description of the coding tree	We provided Figure 1 with categories and themes.
26.	Derivation of themes	We used thematic analysis and themes were identified from the data (see page 10).
27.	Software	We used NVivo Software, see page 9.
28.	Participant checking	Member checking was achieved by paraphrasing and summarizing the participant's contributions during focus groups and interviews. (page 8).
<i>Reporting</i>		
29.	Quotations presented	Yes, pages 11-24.
30.	Data and findings consistent	Yes, pages 11-24
31.	Clarity of major themes	Yes, page 11-24.
32.	Clarity of minor themes	N/A