

# Women's experience of infertility & treatment – A silent grief and failed care and support

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## ARTICLE INFO

### Keywords:

Infertility treatment  
Infertility  
Involuntary childlessness  
IVF  
Experience  
Reproductive trauma

## ABSTRACT

Infertility is one of the components of sexual and reproductive health and rights, but is not as widely addressed as pregnancy, birth, and contraception. Infertility is a global problem, and it is estimated that around 186 million individuals are affected worldwide. Infertility and infertility treatment impact on women's overall wellbeing including their mental, emotional, sexual and spiritual health. Anxiety and depression is prevalent in these women. This study sought to explore the experiences of women going through infertility and IVF in a global context. This study is a metasynthesis with a meta-ethnographic analysis design based on 19 qualitative research studies, including 503 women, focusing on women's experiences of infertility and IVF treatments. Three main themes were identified; the personal reproductive trauma, the impact of and on relationships, and being failed by the healthcare system and society. The personal trauma and experiences included stress, grief, inability to focus, chock, insomnia, anxiety, withdrawing from others, sense of hopelessness and guilt and shame. The infertility and IVF journey also either caused conflicts in relationships or helped the couples to grow stronger. At the same time, relationships with friends and family were strained due to isolation and feeling stigmatized, and not understood. Finally, the healthcare system and providers lacked adequate support, holistic and caring care, and the women felt dehumanized and failed by the healthcare system. It is therefore critical that the healthcare system provide the time, information and support needed to deal with infertility and IVF to maintain quality of life and wellbeing.

## Introduction

Infertility is a global health issue, and it is estimated that around 48 million couples and 186 million individuals are affected worldwide [1]. Infertility has an impact on women's overall wellbeing including their mental, emotional, sexual, and spiritual health, and anxiety and depression is prevalent in these women [2]. Involuntary childlessness is a public health issue and is life-changing for those that experience it, and therefore services and support around reproduction is crucial [3]. Some of those going through infertility are being helped through medical investigations, hormonal treatment, and more advanced support such as in vitro fertilization (IVF). However, for many individuals and couples, remaining childless is a cold fact, which has its roots in society and the health care system, lacking standardized tools and diagnostic protocols to diagnose and treat infertility [4], as well as not having the structure and proper financing to offer health care services [5].

When we dissect "sexual and reproductive health and rights", with

the emphasis on *reproduction* and *rights*, in the context of infertility, one can start understanding infertility support and treatment as a basic right and necessity [6]. Although research shows the prevalence and evidence of the negative impact that infertility and treatments have on women and couples globally, it is still neglected on a policy level which especially impacts people in low- and middle-income countries [7]. United Nations (UN) level policies highly emphasize the prevention of pregnancy and thereby adds to the silencing of the neglectation [8]. Infertility might not be deemed as detrimental or crucial to an individual's and couple's lives, but it is also highly stigmatized in society [7].

Since the onset of assisted reproductive technologies, around 8 million children have been born through treatments such as in vitro fertilization (IVF) [9]. IVF is however not available for most women in developing countries as it is an expensive treatment, and the health care funding varies from country to country [10]. For those that do have access to IVF, it is not always successful at the first attempt and some couples must go through many rounds of IVF before they succeed, if they

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<https://doi.org/10.1016/j.srhc.2023.100879>

Received 25 January 2023; Received in revised form 5 June 2023; Accepted 19 June 2023

Available online 20 June 2023

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ever do succeed. A study by Pinborg et al. [11] showed that a total of around 30 % of couples that had initiated artificial reproductive technology (ART) in a 5-year time frame remained without the birth of a child. The IVF treatments, being invasive and not only putting physical pressure on women, but also emotional and mental, can be traumatic and potentially devastating when not successful [12]. Unsuccessful IVF treatments lead not only to disappointment, but also anxiety, depression, marital issues, non-satisfaction in sexuality and a sense of loss [13].

Infertility is an invisible condition that sometimes is explained as an invisible loss and mourning of something that might not have been seen or felt by others, but that is a dream and hope of a longed-for future [14]. Understanding the experiences of women going through infertility is essential to provide the treatments and support that are necessary for the attainment of health on all levels.

There have been numerous qualitative studies conducted all around the world on the topic of the experience that women have, going through infertility and treatment, therefore, synthesizing the studies already conducted can give a wider perspective on the topic and give space for interpretation. Gaining insights on women's perception and experience of the journey, can help society and the healthcare system to better support women in the process. Therefore, the aim of this study was to explore women's experiences of infertility and infertility treatment.

## Methods

This study is a qualitative metasynthesis [15] with a meta-ethnographic [16] approach. After the formulation of the aim for this study, search terms were chosen specifically to find research studies that focused on the experiences of women diagnosed with infertility (unexplained, sub, primary and secondary) and their experience of any type of infertility treatment.

### Inclusion and exclusion criteria

Qualitative, peer reviewed studies were included which focused on the experiences of the women going through infertility and treatment. Studies with mixed methodology were also included, and the qualitative components are part of the metasynthesis. Studies published from the year 2000 and onward were included, to ensure the relevance of the results for our current time. Studies included are in English and ethically approved. No limitations were set on the physical country location of the studies nor the age of participants. The focus of this research was to study the experience of women going through infertility and treatments which automatically then excludes the partner's experience. Studies that included the partner were still included in the syntheses, but only the experiences and insights from the woman that were meant to carry the child was analyzed. To ensure that the dimension and the intersection of infertility and infertility treatments were at the focal point of the metasynthesis, studies with same-sex or single women going through IVF were excluded from the selection.

### Search strategy

The studies were searched for in Google Scholar, PubMed, Cinhal and PsychInfo (Appendix 1). SPIDER (sample, phenomenon of interest, design, evaluation, research type) search strategy was applied [17] (Appendix 2). Before choosing the articles to be included to the metasynthesis, 447 article titles were read in the search result section of each database, and 56 abstract were read to assure that the studies qualified and met the aim of this metasynthesis. Duplicates were excluded. A total of 27 articles were read and from these, eight were excluded due to either not being peer-reviewed or ethically approved (Appendix 3). A total of 19 were quality assessed according to the JBI Critical Appraisal Checklist for Qualitative Research and all qualified to be included (Appendix 3). All other studies were excluded because of poor quality,

no ethical approval and/or not aligning with the aim of this metasynthesis (Appendix 3).

### Quality assessment

The research studies were quality assured through the Joanna Briggs Institute Critical Appraisal Checklist [18] to ensure highest methodological quality, trustworthiness, relevance, and credibility (Appendix 4). The quality assessment also aimed to investigate if any biases in design, conduct and analysis were addressed, and to make sure that the studies had a high level of trustworthiness. For qualitative studies, the tool included assessment of congruity between stated philosophical perspective and methodology. Thereafter an assessment of the congruity between the methodology and research question, methods used to collect data, analysis, and interpretation of data took place. Furthermore, checking that the researchers had stated where they were located culturally or theoretically was checked alongside checking if the influence of the researcher on the research and vice versa was addressed. Another important assessment was if the participants voices were adequately represented, if there was ethical approval and finally, if the conclusions in the study flowed from the analysis of the data. The total number of articles that got a high-quality score were 19 out of the 19 chosen articles (Appendix 5). See Fig. 1 for the PRISMA flow chart, overviewing the literature search and quality assessment.

### Data synthesis

To find patterns, similarities, and differences, in experiences and behaviors, a meta-ethnographic approach was used for the synthesis [19]. In the process of data extraction and analysis, a matrix was created to get an overview of the studies. This matrix included text segments, metaphors, from each primary study to get a comparable overview of the core concepts [20]. To find the correlations between the studies, text segments were coordinated and placed horizontally to get a clear overview of the correlation between the findings in the primary study. Through this visualization, similarities and contrast were easy to find and metaphors created. Thereafter, a translation of the metaphors into each other furthered the analysis stage in an iterative manner, until the similarities, and lack thereof, were clear and were merged.

## Results

Infertility and infertility treatment have a deep personal impact on women going through the journey. The studies [21–39] were from 12 different countries and four different continents, and there are clear similarities in the lived experience of infertility, although the societal and family norms and expectations could differ from region to region. The analysis of the 19 studies included in this synthesis resulted in three themes and eleven subthemes (see Fig. 2).

### The personal reproductive trauma

#### Purpose and existence

The topic of one's existence and purpose in life was clearly expressed by many women who felt a sense of uselessness and an all-encompassing and overwhelming sense of being "colored" by the infertility journey [21–24]. Women's sense of identity and purpose were negatively affected by infertility and one of the women is questioning the purpose of her existence if she was not going to have a child [23]. Women also described infertility as being "unwomanly" and a sense of inadequacy and worthlessness was present in these women [24–26].

#### Uncertainty and lack of control

The women expressed both a sense of uncertainty and lack of control. This pertained to the overall outcome of the infertility journey and the outcomes of treatment, not knowing what the end result would be, and if

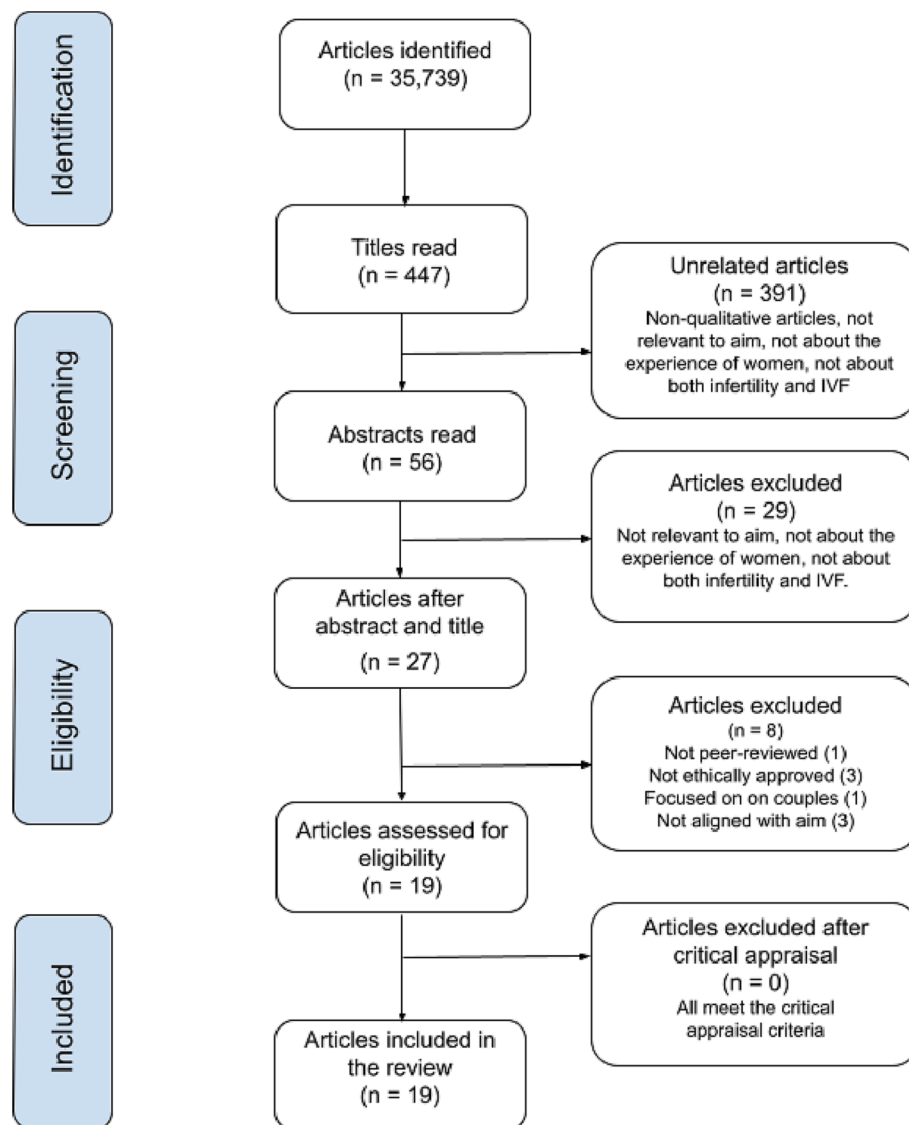


Fig. 1. PRISMA flow chart.

there will be a baby at the end of a long journey [21,23,27–31]. The lack of control was related to the lack of autonomy, being dependent on someone or something else and being controlled by the health care system [21,26,32].

#### *The physical pain caused by invasive treatments and medication*

Just as any life-encompassing disease and treatment, the infertility journey and treatments caused physical discomfort and embodied experiences of pain and hormonal imbalances in women [26,30,21–23]. Beside the emotional trauma, the studies showed that psychosomatic trauma and pain was experienced due to the actual infertility treatments, which resulted in poorer libido, a loss of connection with the body, and hormonal fluctuations that both impacted the emotional and physical state [22,30].

#### *Loss and grief*

Another identified theme was life-grief, which revolved around being childless, not being able to reproduce and not being able to carry forward one's family line [33]. Women also experienced being haunted by their memories of their treatment and had a hard time recovering from their IVF loss [8]. Despair and psychological torture caused insomnia, frustration, fear and anxiety, and adjustment to the

treatments was not easy [22,26–27]. Another aspect was the psychological effect that an embryo-loss had during treatments due to, as one of the participants described, the sense that the embryo was a material representation of the possible future child [30]. The loss of this is thus experienced as a loss of a child and is as painful as mourning a child in their experience, within our outside of the womb. Another woman experienced childlessness as a form of pain and that the fertilized egg was indeed experienced as a child, and when menstruation came, it was experienced as a miscarriage no matter the age of the embryo [33]. The sense of loss that was expressed by the women in the studies resulted in a mourning and grief similar to the one that occurs when there is a physical loss of a loved one [25].

#### *Loneliness and isolation*

The experience of infertility and going through treatments was widely described as a lonely road where disclosure was not always a comfortable choice due to stigmatization and the fear of judgment [24–25,28,31,34]. The grief was also a lonely process for many as they experienced that others around them, who did not have the same experience, could not fully understand the vast fullness of the grief and loss experienced due to infertility and treatment failures [23–24,28,35]. The loneliness was also experienced after failed treatments, when the

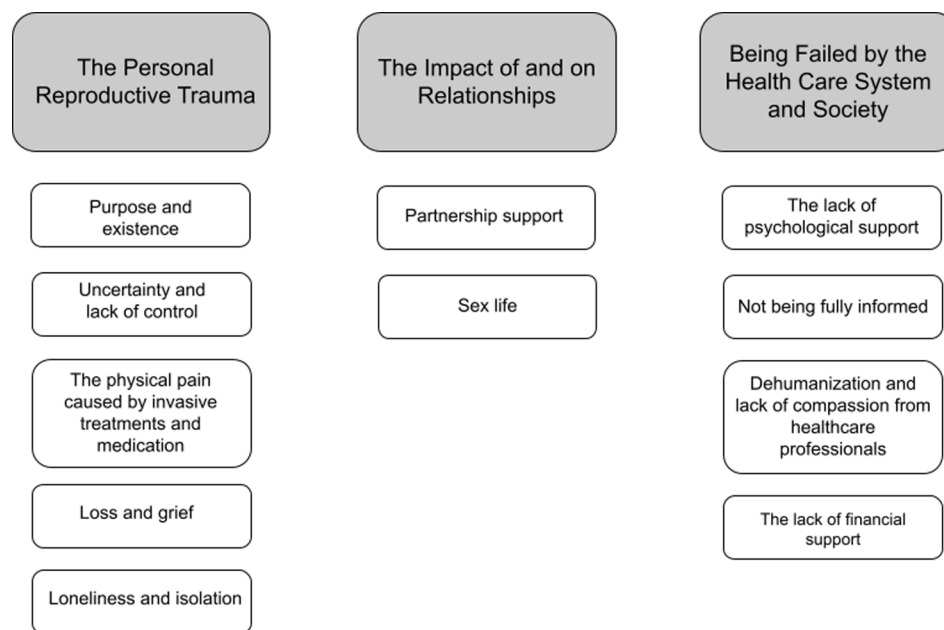


Fig. 2. Overview of themes and subthemes.

health care system no longer provided support, and they felt abandoned in their grief [34]. Another common issue that arose in women was the difficulty relating, engaging and being around other “fertile” women with their own children and thereby more isolation was created [23]. A woman admitted that she felt more comfortable sharing her story with women going through the same process and that “childless women understand each other” [28, 7, pg. 532].

#### *The impact of and on relationships*

##### *Partnership support*

Tension and negative feelings like stress created some discord in the marriage of some of the women, and one woman expressed that the experience tested people’s relationships to the limit [21]. Women reported that they had received support from partners in terms of being accompanied to the clinic, assuming housework and taking care of them at home which also helped with their wellbeing [22]. Some women even felt that they had experienced a deeper intimacy with their partner as they were going through this journey together [32].

##### *Sex life*

The studies show how the infertility journey and treatments affected women’s sex lives and libido negatively [27,30,36–37]. The loss of spontaneity, the planning of intercourse around the cycles, paired with side effects due to the hormonal medication, all lead to a decrease in libido. Some also experienced vaginal dryness and sensitive breasts [30]. Women reported less pleasure and a decrease in sexual activity and in two cases, the women had not had sex in years due to their infertility journey [30].

#### *Being failed by the health care system and society*

##### *The lack of psychological support*

The women in the studies expressed a lack of emotional and psychological support from the health care staff and system [25,27,32,34,21–23,36–38]. In one of the studies, the majority of the participants reported that they wished to have counseling and more information before, during and after treatments [35]. Women reported that no counseling was given by physicians and that the psychological effects of IVF treatment were overlooked [21,35]. The women also

reported that there was a lack of support when it came to handling the grief after IVF failure and that it was not until they ended treatment that they understood that this type of support was truly necessary [25].

##### *Not being fully informed*

Women reported not knowing the full spectrum of treatment options and the medication that they received, and that even some of the health care staff lacked knowledge in this area [25,35,38]. Women also felt uninformed about the long-term effects of treatment, on themselves and on their fetus and possible child [29,34,38–39]. Concerns were expressed around the health impact of ovarian hyperstimulation syndrome and fear of breast and uterine cancer as result of the hormonal treatment of IVF [38]. Furthermore, women expressed that they had concerns about their fertility investigation, feeling that they had not been fully evaluated and examined in regard to unexplained infertility [25]. Women explained that the lack of information actually deepened the stress and that the doctors should explain everything from the very beginning to give an indication of the risks, chances and possibilities [38].

##### *Dehumanization and lack of compassion from healthcare professionals*

Women reported a sense of dehumanization when going through treatments and treated in a condescending way [21]. They felt that they had very limited time for inquiries at the doctor appointments and a lack of involvement in the decision making in their healthcare [22]. They experienced a careless healthcare environment which was unempathetic, lacking of sensitivity of the emotional impact it had, as well as little caring communication [27]. This led to a lack of trust and not disclosing fully how they were feeling and thinking to their healthcare professionals [36]. The physical aspects of infertility were focused on solely by the physicians with little sensitivity to the personal and emotional experience, which led to further isolation [34]. Insensitive and impersonal care paired with the lack of guidance toward self-help practices and support groups, all colored the experience for the women in a negative way [23].

##### *The lack of financial support*

Women experienced that there were not enough governmental policies that supported them and that they needed to use sick days and leaves during the treatment days [36]. They also experienced a lack of

support from the government when it came to finances, and the treatment led for some to financial difficulties [28].

## Discussion

The results of this metasynthesis provide evidence that the infertility journey and infertility treatment have a physical, psychological, emotional, sexual and spiritual impact on women's lives. On a personal level it causes trauma and grief, and on a relational level it causes distress in the relationship with the intimate partner and others in the woman's life. Finally, the health care system and society does not provide adequate support to women with infertility and they feel failed and dehumanized by the healthcare system.

The reproductive trauma that infertility and infertility treatment instill causes an existential crisis alongside grief, pain and loss. In line with this finding, Diamond [40] explains that the reproductive trauma derives from the disruption of one's personal identity and story that one carries about motherhood and becoming a mother, from childhood and adolescence, into adulthood. Another aspect of the trauma is reproductive loss, which refers to everything from termination of a pregnancy, miscarriage, perinatal death, stillbirth, neonatal death, to failed IVF cycles [41]. Such loss was also expressed by women in this metasynthesis.

The results also indicate that the intimate relationship with partners can be strained due to the long treatments, stressful appointments and the change of mood and libido that occurs due to the trauma of infertility, medications and treatments. A solution to this has been presented in a study by Read et al. [42], where couples expressed a desire for counseling to be able to talk through the infertility experience and instead grow stronger by this experience.

Furthermore, the metasynthesis shows that there is a lack of support in society and by the healthcare system and from healthcare professionals. This experience is reflected in a study by Malin et al. [43], which showed that that dissatisfaction with treatment is correlated to a poor relationship with health care staff. The study emphasized the importance for a physician to have time for the woman and listen, as well as having a correct diagnosis and selecting appropriate care. In addition, Read et al. [42] who investigated what type of support couples in infertility treatment want and need, showed that seeing a psychologist, support groups, peer members, online forums and information resources was sought for to resolve stress, relationship issues, sharing experiences with others and getting practical information.

Women's experience with healthcare professionals, lacking empathy, compassion and understanding, was a repeated incident in this metasynthesis. Read et al. [42] highlight these experiences in their study, which shows that negative experiences in treatment are connected not only to the outcome, but also the experience with physicians being unempathetic, disrespectful, impolite and objecting the woman to only her "diagnosis", ignoring personal/individual and subjective aspects of childlessness, and the importance of woman-centered-care. The same study also outlined physicians rushing and being in a hurry at the appointments, hurting the women in examination, as well as giving blunt unempathetic answers.

Qualitative studies are interpretative in their nature and discernment is important throughout the process. This metasynthesis was based on qualitative articles with high quality according to the JBI Critical Appraisal Checklist for Qualitative Research [18]. The four ethical principles from the Helsinki Declaration [44] were foundational for this study and were taken into consideration when searching for and reading the studies. The strengths of this study and the methodology used are that through this metasynthesis of 19 studies, we have been able to

capture over 500 women's experiences if infertility and IVF, as well as that we have the insights from 12 different countries and cultures, which makes this metasynthesis more diverse and inclusive than an empirical qualitative study. As we know it, there is to date no other metasynthesis with meta-ethnographic approach of women's experience with infertility and IVF. In the case of countries with a heterogeneous population, the authors did not always disclose the cultural or ethnic backgrounds of the participants. This makes it hard to know if the studies were indeed inclusive enough to reflect the varieties of cultural and ethnic backgrounds that are present. The matter of transferability would have been strengthened if there was an equal proportion between high, middle- and low-income countries. Regrettably, when searching for articles containing both infertility experience and IVF, naturally most studies were from countries where treatment is more accessible. This creates a discrepancy when it comes to representation and inclusion, which is a prevalent theme in the history of medicine and healthcare research and when it comes to selection bias.

The results of this metasynthesis also provide insights of the lack of knowledge, insights and maybe also the lack of interest from healthcare providers to truly understand the impact that infertility, infertility evaluation and treatment has. Empathy, care and counseling can be the key to assert more comfort to these women and to provide the services that they deserve and is the foundation of successful woman-centered-care.

## Conclusions

The results of this metasynthesis provides a foundation for deeper understanding of women's experiences of infertility and treatment that policy makers, the healthcare system and healthcare providers need in order to provide necessary services and support.

Infertility is a silent "disease" not fully understood, supported, or communicated in society. It has major implications for those that experience it, and women are carrying the burden of stigmatization, trauma, grief, invasive treatments, and lack of empathy, support and compassion. The trauma of infertility needs to be addressed in the level of global sexual and reproductive health and rights, with strategies and policies in place to provide adequate services in terms of physical, emotional, mental, psychological, and financial support.

Infertility treatments should be understood as essential and life-altering, for the better or worse. Women should also be screened, just as in the case of new mothers that have given birth, during fertility investigation and treatment for anxiety, depression and PTSD. It is essential that services are not only focused on the physical aspects of infertility, but that they are more holistic and go beyond only the physical. Furthermore, health care professionals, on an individual level, must be able to provide compassionate and empathetic care and understand that failure of this can increase the trauma that the women are already experiencing. Giving the adequate information and time, empowering women in the process and making sure that they are met with the time and support that they have the right to, have to be part of the care that is given. This is a sexual and reproductive right.

This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

## Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.



## Appendix 1. Literature search

Database	Search term	Limitations	Total hits	Read titles	Abstracts Read	Articles Read	Quality assessed articles	Number of articles in the metasynthesis
1. PubMed	Infertility AND Treatment AND Experience AND Qualitative	From 2000	253	50	7	4	4	2
2. PubMed	Experiences AND Women AND Infertility AND Qualitative Research	From 2000	220	20	2	2	2	1
3. PubMed	Experiences AND Women AND Infertility AND In vitro Fertilization	From 2000	300	30	2	1	1	1
4. CINAHL	Experiences AND Infertility AND Qualitative AND Women	From 2000	160	30	5	4	4	4
5. CINAHL	Lived Experience AND Infertility or (Infertile or Fertility Issues) AND Women	From 2000	78	78	5	3	3	2
6. PubMed	Unsuccessful AND Infertility treatment AND Involuntary Childlessness	From 2000	5	5	5	1	1	0
7. PubMed	Unsuccessful and In Vitro AND Women	From 2000	237	20	1	1	1	1
8. CINAHL	Childlessness AND After AND In Vitro Fertilization	From 2000	8	8	1	1	1	1
9. Pubmed	Women AND Experience AND Infertility Treatment AND (Grief OR Mourning)	From 2000	8061	21	4	1	1	1
10. Google Scholar	Lived Experience AND Pain AND Women AND IVF Treatment	From 2000	17.500	30	4	1	1	1
11. Google Scholar	Experience AND “Infertility Treatments”	From 2000	8450	20	2	1	1	0
12. CINAHL	Unsuccessful AND Infertility Treatment AND Involuntary Childlessness	From 2000	75	30	3	1	1	0
13. PsychInfo	Assisted Reproductive Treatment AND Women AND Infertility AND Unsuccessful	From 2000Peer reviewed	5	5	2	1	1	1
14. PsychInfo	Infertility AND Treatment AND Experience AND Qualitative	From 2000Peer reviewed	138	40	7	4	4	3
15. PsychInfo	Women AND Infertility Treatment AND Mental Health	From 2022Peer reviewed	249	60	6	1	1	1

## Appendix 2. SPIDER search strategy

S	“women” or “woman”
PI	“infertility” or “childlessness” or “unexplained infertility” or “involuntary childlessness” or “IVF” or “in vitro fertilization” or “in vitro” or “infertility treatment” “infertility” or “IVF” or “infertility treatment” or “assisted reproductive technology”
D	“interview” or “focus group”
E	“experience” or “lived experience” or “feeling” or “challenges” or “wellbeing” or “mental health” or “grief” or “mourning”
R	“qualitative” “thematic” “content analysis” “ethnographic” “phylogeographic” “hermeneutical analysis”

## Appendix 3. Excluded articles

Author(s) (year)	Aim	Design, method	Participants	Results	Reason
Mosalanejad, L., Parandavar N., Gholami3 M., Abdollahifard S. (2013)	The purpose of this study was to explore the lived experience of infertile women from increasing and decreasing factors of hope in infertile women with failure in infertility treatment	Qualitative. Semi-structured interviews. Analyzed using interpretive research strategies of phenomenology by Collizi's seven-stage method	23	The increasing factors which emerged from the data contain “spiritual source”, “family interaction and support” and “information through the media”, and decreasing factors contain “nature of treatments” and “negatively oriented mind”.	Not peer-reviewed
Öztürk, R., Herbell K., Bloom, T. (2021)	This study aimed to describe women's experiences regarding infertility and explore factors that women find helpful to alleviate their fertility-related stressors.	Mixed methods. Qualitative In-depth interviews, qualitative description analysis.	12	“...significant stressors that women encounter in their fertility journey including a desire for empathetic, understandable, and effective treatment and support, and the crucial role of healthcare providers”	Not ethically approved
Webair, H. H, Ismail, S. B., & Khaffaji, A. J. (2021)	The current study aims to define patient- centered infertility care (PCIC) from the perspective of Arab women with infertility	Qualitative. Semistructured in-depth telephone interviews. Inductive thematic analysis.	14	Participants highlighted nine important PCIC dimensions. Of these, four were agreed on by all participants: accessibility, minimizing cost, information and education, and staff attitudes and communication. The remaining five dimensions were staff competence, physical comfort, privacy, psychological and emotional	Not aligned with the aim of the synthesis.

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Author(s) (year)	Aim	Design, method	Participants	Results	Reason
Tiu, M. M., Hong, J. Y., Cheng, V. S., Kam, C. Y., & Ng, B. T. (2018).	This study aims to explore and describe the phenomenon of women with infertility and to enhance understanding on how infertility affects their lives and the specific social consequence they encountered.	Qualitative phenomenological design. Thematic analysis.	13	support, and continuity and coordination of care. Four themes emerged in the study, including (i) non-escapable cultural burden in Chinese family; (ii) psychological distress: isolation caused by envy; (iii) disappointment towards reproductive health services; and (iv) self-compassion and religion as coping strategies.	No indication that it was ethically approved
Wirtberg, I., Moller, A., Hogstrom, L., Tronstad, S-E., & Lalos, A. (2006).	The aim of this study was to obtain an increased knowledge and deeper insight into the long-lasting effects of, and coping with, involuntary childlessness for a group of women who had sought help for infertility and had completed infertility treatment over 20 years before.	Qualitative. In-depth interviews. Theme analysis.	14	The childlessness had had a strong impact on all the women's lives and was for all a major life theme. The effects were experienced both on a personal level and on interpersonal and social levels.	Not aligned with the aim of the synthesis.
Daniluk, J. C. (2001)	This study explored how couples who have been unsuccessful in achieving a viable pregnancy through medical fertility treatments live with, and retrospectively make sense of, their experiences with medical treatment.	Qualitative. In-depth interviews. Narrative analysis.	65 couples	These findings provide some direction regarding the needs of infertile couples for information, support, and advocacy during the pursuit of medical solutions to their infertility.	Not aligned with the aim of the synthesis.
Bergart, A. M. (2000)	To offer guidelines for social workers and medical professionals to meet the needs of infertility patients after failed interventions.	Interviews		The findings of this study suggest that women often need help with the intense emotions stimulated by the treatment experience.	No approval stated
Wilkes, S., Hall, N., Crosland, A., Murdoch, A., & Rubin, G. (2009)	The aim of this study was to explore the reasons underpinning the attitudes and perceptions of the primary care patient experience of infertility management in Northumberland and Tyne and Wear in North-East England.	Qualitative. In-depth interviews. Grounded approach. Constant comparison.	22	Factors that influenced a couple's experience of infertility management were personal and professional relationships, patient autonomy in decision making and access to services.	Focus on couple's experience

#### Appendix 4. JBI Critical Appraisal Checklist for Qualitative research



## JBI Critical Appraisal Checklist for Qualitative Research

Reviewer \_\_\_\_\_ Date \_\_\_\_\_

Author \_\_\_\_\_ Year \_\_\_\_\_ Record Number \_\_\_\_\_

	Yes	No	Unclear	Not applicable
1. Is there congruity between the stated philosophical perspective and the research methodology?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Is there congruity between the research methodology and the research question or objectives?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Is there congruity between the research methodology and the methods used to collect data?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Is there congruity between the research methodology and the representation and analysis of data?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Is there congruity between the research methodology and the interpretation of results?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Is there a statement locating the researcher culturally or theoretically?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Is the influence of the researcher on the research, and vice-versa, addressed?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Are participants, and their voices, adequately represented?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Overall appraisal: Include ☐ Exclude ☐ Seek further info ☐

Comments (Including reason for exclusion)

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## Appendix 5. Included articles in the metasynthesis

Nr	Author (year), country	Country	Title	Aim	Design, method	Participants	Age group	Results	Quality
1	M. Redshaw, C.Hockley & L. L. Davidson (2006)	UK	A qualitative study of the experience of treatment for infertility among women who successfully became pregnant	The aim of the present study was to increase the understanding of how women experience treatment and care by using their own words as the starting point and to indicate ways in which practice and care might be improved.	Qualitative: A semi-structured postal questionnaire. Thematic analysis.	230	Not disclosed	“Emergent themes related to the treatment process, pain and distress, lack of choice and control, timing, emotional and financial costs, fairness and contrasts in care”	High
2	Li-Ying Ying, Lai Har Wu1, Alice Yuen Loke1 (2015)	China - Hong Kong	The Experience of Chinese Couples Undergoing In Vitro Fertilization Treatment: Perception of the Treatment Process and Partner Support	This is a qualitative study intended to explore Chinese couples' experience of IVF treatment, especially their perceptions of the treatment process and the support between marital partners.	Qualitative descriptive approach. In depth-interviews. Content analysis to describe a phenomenon.	12	28–40	“The four themes that were identified were: the process of hardship, the endurance of hardship with a loving relationship, partnership in couples, and ambivalence towards social support. The findings offer insights into the sufferings of IVF couples and point to the need for a supportive program for infertile couples...”	High
3	Ilkay Boz & Hu Iya Okumus (2017)	Turkey	The “Everything About the Existence” Experiences of Turkish Women With Infertility: Solicited Diaries in Qualitative Research	The aims of this study are to investigate the infertility experiences of women using Watson’s Theory of Human Caring as a guide and to sensitize healthcare professionals to the importance of the personal stories of these women.	Qualitative. Solicited diaries. Thematic analysis.	18	18–45	“The findings identified the following themes: (a) losing control of everything, (b) facing up to the angst, (c) living with the unknown, (d) alienation from the fertile world, (e) existential faith and hope, and (f) nonhealing environment.”	High
4	Miok Kim, Su Jeong Yi, and Ju Eun Hong (2020)	South Korea	Experiences of Women with Male Factor Infertility under In Vitro Fertilization	This study attempts to explore the experiences of infertility among women with male factor infertility.	Qualitative. Phenomenological study. Qualitative analysis through themes.	9	34–41	The analysis indicated that the women’s infertility experiences were structured into five theme clusters: “Difficult to accept the situation”, “Confused inside”, “Destroyed relationships due to blaming and anger”, “Desire social support”, and “Embracing hurt feelings and regaining strength”	High

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Nr	Author (year), country	Country	Title	Aim	Design, method	Participants	Age group	Results	Quality
5	Syeda Shahida Batool & Richard Oliver de Visser (2016)	Pakistan and UK	Experiences of Infertility in British and Pakistani Women: A Cross-Cultural Qualitative Analysis	The aim was to explore the experiences of infertile women in two different cultures.	Qualitative. Cross-cultural. In-depth, semi-structured interviews. Phenomenology.	14	24–46	The findings presented here illustrate that although infertile women in the United Kingdom and Pakistan had many shared experiences, they also experienced unique challenges shaped by their cultural contexts.	High
6	Zohreh Khakbaban, Raziye Maasoumi, Zahra Rakhshae, Saharnaz Nedjat (2020)	Iran	Exploring Reproductive Health Education Needs in Infertile Women in Iran: A Qualitative Study	The present qualitative study aimed to explore the experiences and educational needs of infertile women with regard to reproductive health.	Qualitative. In-depth, semi-structured interviews. Content analysis.	20	25–46	In infertile women, the educational needs associated with reproductive health are multifaceted. Satisfying these needs can help achieve optimal treatment results and promote reproductive health.	High
7	Samiye Mete, Sevcin Fata, Merlinda Aluș Tokat (2019)	Turkey	Feelings, opinions and experiences of Turkish women with infertility: A qualitative study	This qualitative study aimed to reveal the experiences, feelings and opinions of Turkish women with infertility	Qualitative. Internet forums. Content analysis.	26	Not disclosed	The themes which emerged were psychological changes, changes in social life and changes related to treatment themes. Holistic approach and patient-specific interventions can help turn the above mentioned vicious cycle into positive.	High
8	M. Patrice McCarthy, RN, CNS, PhD (2008)	USA	Women's Lived Experience of Infertility After Unsuccessful Medical Intervention	The purpose of this qualitative descriptive study was to explore the phenomenon of women's experience with infertility in the aftermath of unsuccessful medical treatment.	Qualitative descriptive study. Interviews. hermeneutic–phenomenological	22	33–48	Women described the existential challenges to their sense of self, their identity, and the meaning and purpose of life. The paradoxical dimensions of loss and opportunity in their experience contributed to an altered view of themselves and their world. Infertility and its role as a life-defining experience pervaded their stories of living with infertility after unsuccessful treatment.	High
9	Hellen Allan (2006)	UK	Experiences of infertility: liminality and the role of the fertility clinic	The aim of the research was to voice the meanings of fertility and infertility for patients and staff and analyze how these shaped	Qualitative. Semi-structured interviews and Ethnographic methods to participant observation. Modified thematic analysis.	15	Not disclosed	The findings discussed in this paper show that infertility was described by women as a chaos or social dis-ease where infertile women's relationships with	High

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Nr	Author (year), country	Country	Title	Aim	Design, method	Participants	Age group	Results	Quality
				patient needs and nursing practice.				fertile women were experienced as emotionally risky	
10	Tsann-Juu Su, Yueh-Chih Chen (2006)	China - Taiwan	Transforming Hope: The Lived Experience of Infertile Women Who Terminated Treatment After in Vitro Fertilization Failure	The purpose of this study was to explore the lived experience of infertile women who terminated treatment after in vitro fertilization (IVF) failure.	Qualitative. Telephone Interviews, analyzed using interpretive research strategies of phenomenology	24	32–47	The theme of lived experience which emerged from the data was “transforming hope”. This theme included three categories: [1] accepting the reality of infertility, [2] acknowledging the limitations of treatment involving high technology, and [3] re-identifying one's future.	High
11	Helena Volgstén, Agneta Skog Svanberg & Pia Olsson (2010)	Sweden	Unresolved grief in women and men in Sweden three years after undergoing unsuccessful in vitro fertilization treatment	Explore the experience of undergoing unsuccessful in vitro fertilization (IVF) treatment and of remaining childless 3 years after IVF in both women and men	Qualitative. Semi-structured interviews. Qualitative content analysis.	10 women, 9 men	Women: 35–43		High
12	Marianne Johansson & Marie Berg (2005)	Sweden	Women's experiences of childlessness 2 years after the end of in vitro fertilization treatment	The aim of this study was to describe women's experiences of ongoing childlessness 2 years after the end of IVF treatment.	Qualitative. Interviews. Phenomenology.	8	Not disclosed	The essence of all constituents is 'life-grief' and expresses the grief of being childless, of not reproducing, and being unable to confirm one's relationship through parenthood. The result is important in professional caring and presents a challenge to all midwives, nurses, physicians and other staff who are involved in the care of involuntarily childless women.	High
13	Marjolein Lotte de Boer, Hilde Bondevik, Kari Nyheim Solbraekke (2019)	Netherlands	Beyond pathology: women's lived experiences of melancholy and mourning in infertility treatment	We offer an exploration of melancholy and mourning beyond this pathological ailing/healing logic. We do so by asking what it means for women to actually live with melancholy and mourning in infertility treatment	Qualitative. In-depth interviews. Interpretative research method.	10	29–45	In answering this question, we show that women in infertility treatment may have different kinds of melancholic longings: they desire their lost time as a pregnant woman, lost love life and lost future.	High
14	Hilla Ha'elyon & Chen Gross (2011)	Israel	The “Lived Pain” Experience: The Case of Women	This research used the embodied approach to analyze the pain	Qualitative. Semi-structured interviews.	25	25–45	The research findings suggest that women who share the same socio- cultural	High

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Nr	Author (year), country	Country	Title	Aim	Design, method	Participants	Age group	Results	Quality
			Undergoing IVF treatments	experiences of 25 heterosexually married Israeli-Jewish women undergoing in vitro fertilization (IVF) treatments for a first pregnancy				environment (Israeli pronatalism) and physical circumstances (the inability to conceive) have varied and wide ranging interpretations of pain.	
15	Anna Bailey, Helen Ellis-Caird & Carla Croft (2017)	UK	Living through unsuccessful conception attempts: a grounded theory of resilience among women undergoing fertility treatment	This study aims to fill this gap in literature and contribute to the theoretical understanding of the process of resilience among women undergoing assisted reproductive treatment.	Qualitative. Semi-structured interviews. Grounded Theory.	11	24–42	Three core categories were identified: 'Appraisal'; 'Stepping away from treatment'; and 'Building self up for the next attempt'. Following the failure of treatment, participants appraised their ability to carry on with further treatment attempts.	High
16	Athena Pedro and Brendon D. Faroa (2017)	South Africa	Exploring the lived experiences of infertility treatment and care by involuntarily childless women	This study sought to explore the fertility treatment experiences of South African women with involuntary childlessness from suspected infertility.	Qualitative. Semi-structured interviews. Thematic analysis.	21	26–41	Four main themes were identified in the study; including: lack of compassionate care from treatment care providers, the need for infertility clinics to integrate psychosocial support care, a need for continuing education for fertility staff, as well as financial support resourcing.	High
17	Anjali Widge (2005)	UK	Seeking conception: Experiences of urban Indian women with in vitro fertilization	The specific questions explored were how urban Indian women undergoing IVF experience the social context of infertility; how they experience certain aspects that are related to IVF treatment (such as the process of investigations, physical, emotional and financial costs); their attitudes towards adoption and perceptions of IVF treatment.	Qualitative. In-depth interviews. Thematic analysis.	22	29–42	In-depth interviews revealed that infertility is deeply feared, women's status and security are affected, and they experience stigmatization and isolation. IVF was pursued after less intrusive avenues had been exhausted. Inadequate information/counseling is provided, success rates are low, IVF is commercialized and the process is physiologically, emotionally and financially stressful.	High
18	Nicola Cunningham	UK	Women's experiences of	The aim of this study is to	Qualitative. Interviews. Layered strategy influenced by the voice-	9	28–44	Women reveal a complex	High

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Nr	Author (year), country	Country	Title	Aim	Design, method	Participants	Age group	Results	Quality
	and Tom Cunningham (2013)		infertility – towards a relational model of care	enhance this knowledge by drawing from an earlier study exploring women's life-story accounts living with and through infertility.	centered relational method, emphasizing narrative content, form and function.			experience. Three key themes were found: Approaching the clinic narratives are infused with personal expectations while deeply reflective of cultural expectations and social norms. Relatedness recognises women's experiences cannot be neatly separated into distinct domains. Liminality and infertility describes women's experiences lost in transition through and beyond infertility treatment.	
19	Funda Çitil Canbay, Elif Tuğçe Çitil, Tuğba Şadiye Çitil Şap and Osman Şap (2021)	Turkey	Identifying Experiences and Hopelessness Levels of Women Receiving Infertility Treatment: A Mixed Method Study	The research aimed to identify experiences and hopelessness levels of women receiving infertility treatment.	Mixed method - quantitative and qualitative. Interview. Thematic analysis.	20	20–51	Four themes were found in the qualitative dimension about infertility and the treatment process. It was seen that Turkish women did not have sufficient knowledge about the process of infertility and treatment and had a high level of hopelessness.	High

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