

Are the barriers to accessing Assisted Reproductive Technology (ART) and the perceived experiences of care among different ethnicities of subfertile women similar across Africa and Europe? A systematic review and thematic synthesis of qualitative studies

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ABSTRACT

Background:

Although there is an increasing awareness that subfertility constitutes a serious public health issue, few studies consider how the experience of different ethnicities of women accessing Assisted Reproductive Technology (ART) is formed by their particular social positions. Effective strategies that address structural and sociocultural barriers to ART are required to mitigate its potential long-term physical, financial and psychological effects in order to inform the design of more inclusive and supportive interventions.

Methods

Electronic databases including MEDLINE, EMBASE and Pubmed as well as grey literature were systematically searched for studies published from 1978 to 02 December 2020. Inclusion criteria with respect to eligibility and quality were applied. Qualitative data was extracted on content and methods, then critically appraised for methodological quality using the CASP toolkit. The findings of eleven qualitative studies were combined using thematic synthesis and organised according to patients' experience and assessment of service quality and dimensions of patient-centredness. Additionally, data on the sociocultural barriers that may impact patients' perspective on care was collected. The thematic synthesis consisted of three stages: coding of text 'line-by-line'; the development of 'descriptive themes' and the development of 'analytical themes'.

Results

This review explores the perceptions of illness, subfertility and the ability to access ART of subfertile women across West Africa ($n = 4$); South Africa ($n = 3$); Central Africa ($n = 1$) and Europe ($n = 3$). Six themes emerged relating to each perceived quality of care and perceived barriers to accessing ART. The complex health seeking behaviours of women revealed they sought biomedical and holistic treatment as well as help from Christian and Islamic places of worship. Although treatment choice was related to the perceived aetiology of subfertility, it was also influenced by perceived access to effective treatment. Those from a lower socioeconomic background who faced barriers to treatment were also more likely to be confronted with the social stigma of subfertility as well as intimate partner violence.

Conclusion

The lives of subfertile women were characterised by social suffering incurred from gender and pro-natal norms, cultural beliefs and practices as well as limited access to ART. An intersectional approach may be used to inform public health strategies and social policy by highlighting how in particular scenarios, certain groups may experience greater barriers accessing ART and thus are more vulnerable than others. Services may need to invest in working with organisations, like the British Fertility Society, to promote a more patient-centred service offering better integrated care and support to encourage wider engagement.

Keywords

Patient Experience; Infert*; Africa; Ethnic*; Stigma; Mental*; Quality, Care; Health-seeking Behaviour; Assisted Reproductive Technology; IVF; Patient—Centred

LAY SUMMARY

In this review, subfertility is understood to be a condition where women are unable to bear or have children following previous pregnancies. Not much is known about which women report fears of subfertility or how it affects the actions they take to get better, such as provider type sought. To learn more about it, studies were searched to explore the experiences of women who use European and African healthcare systems whilst they cope with being unable to have children (subfertile) and deal with potential stigma, physical and emotional abuse from their family and community.

Being subfertile affected how subfertile women were treated by their partners, relatives and friends in different ways depending on their wealth, education and religion. Results showed the risk of developing long-term mental health and financial issues whilst accessing fertility treatment (ART) may vary according to where you live in the country. As being able to use ART was dependent on their ability to find, be seen by a helpful doctor and pay, ART was limited mostly to women able to afford it without help from the government. Fear also influenced how they sought treatment. For example, the fear that their subfertility was God's punishment for past misbehaviour and the lack of affordable, high quality ART services nearby led some women to seek traditional healing and spiritual mediation despite the risk of financial exploitation or harm. Poorer women were found more likely to face abuse from their partner, family-in-law and community. Muslim women feared that their husband would divorce them or marry an additional wife. As a result, women, particularly those of African origin were vulnerable to emotional and physical abuse and suffered greater financial consequences.

This review helps to ensure better understanding among those providing services about how to target, prioritise and allocate money to better meet the needs of subfertile women across Africa and Europe.

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1.0 INTRODUCTION

1.1 Subfertility: Definition and global burden

Subfertility is defined as a failure to conceive after 12 months of unprotected regular sexual intercourse (Zegers-Hochschild et al. 2009). Most couples presenting with a fertility problem have relative subfertility with a reduced chance of conception because of one or more factors in either one or both partners rather than absolute infertility (Taylor 2003). A study initiated by the World Health Organisation, WHO estimated that 1.9% of women aged 20 - 44 years old, which equates to 20 million couples, are affected by primary subfertility worldwide (Lampic et al. 2006; Mascarenhas et al. 2010). Additionally, 10.5% of women were reported to be unable to have a second live birth after the first, thus suffering from secondary subfertility. Both primary and secondary infertility has been estimated to affect 48.5 million couples worldwide (Kitchen et al. 2017; Vikström Eckevall 2016). In the UK, subfertility is a huge public health problem that affects approximately 1 in 7 couples¹ (National Institute for Health and Clinical Excellence 2013). The advancement and acceptance of infertility treatment in the UK has been significant (Maalouf et al. 2017). However, unlike other areas of medicine, there is a paucity of robust evidence related to the relationship between ethnicity and the experience of accessing infertility treatment (Maalouf et al. 2017). As health authorities have not collated ethnicity data systematically, establishing whether there is an impact of ethnicity has become challenging (Jones 2013). It is possible that the under-reporting of ethnicity may have contributed to the under-studying of race as a potential factor driving a possible difference in the experience between different ethnicities of subfertile women accessing fertility services in the UK. For example, the treatment protocols for in vitro fertilisation (IVF) or intracytoplasmic sperm injection (ICSI) treatment for women were based on solely on body mass index (BMI), age, ultrasound and endocrine markers of ovarian reserve (Maalouf et al. 2017).

Furthermore, most treatment protocols are based on research studies which were conducted in Europe and North America, where the majority of the population is Caucasian (Maalouf et al. 2017). Applying these conclusions and practices to populations across other continents with varying ethnicities and races may thus be problematic. Studies highlight the risk of depressive symptoms and suicidal ideation in subfertile women accessing infertility treatment increases with nulliparity², primiparity³, denial, social withdrawal and self-blame coping strategies (Shani et al. 2015). There are few published studies highlighting ethnicity as a determinant factor of importance in the risk of suicidal ideation among subfertile women accessing and utilising IVF/ ICSI treatment (Shani et al. 2015). This may be attributable to most studies being based on small sample sizes with the inclusion of subjects of ethnicities and races that are not representative of the general population and larger studies being based on the population of Northern America (Maalouf et al. 2017). Most published data pool different ethnicities under wider categories that are significantly racially and ethnically different (Maalouf et al. 2017). For example, women from Bangladesh and Japan fall under one homogenous group, ‘Asian’, resulting in a number of under-represented ethnic groups (Maalouf et al. 2017). However, the greatest proportion of Black people are African and Caribbean

¹ Please note, the studies do not specify whether these estimates include same-sex couples.

² Nulliparity refers to women who have ‘never given birth to a viable infant’ (Hughes 2018; National Institute for Health and Care Excellence 2017)

³ Primiparity refers to women who have ‘borne at least one viable offspring (usually more than 24 weeks of gestation)’ (Hughes 2018; National Institute for Health and Care Excellence (2008)

(8.9% and 3.2% respectively) and the greatest proportion of Asian people are Indian (10.7%), Pakistani (6.6%), Chinese (4.0%) and Bangladeshi (2.9%) (ONS 2015) (Appendix A Table 1.0).

1.2 Immigration, Psychosis and Suicidal Ideation

1.2.1 Stigma and the Risk of Psychosis

Empirical evidence suggests mental health disparities are the likeliest in migrants and ethnic minorities who have often experienced physical and emotional trauma or suffer indicators of social disadvantage (Forte et al. 2018; Cantor-Graae & Selten 2005; Brugha et al. 2004). These indicators include the degree of social isolation, unemployment and social class (Schofield et al. 2010; Fearon et al. 2006; Brugha et al. 2004). A cohort analysis of the risk of adult suicide between 1982 and 2002 found that one in ten suicides recorded in UK general practice is attributable to severe mental illness, SMI (Osborn et al. 2008). As ethnic minorities are at greater risk of all psychotic illnesses and improving the lives of people living with mental illness is a public health priority, it is now important to explore the social context in which subfertile African women in Europe access fertility treatment (Lindert et al. 2009; Fearon et al. 2006; Lloyd et al. 2005; Cantor-Graae & Selten 2005).

Infertility prevalence rates of 30-40% are reported in parts of sub-Saharan Africa (Hammarberg & Kirkman 2013; Leke et al. 1993). In a study combining data from 47 demographic and health surveys in developing countries it was estimated that 186 million ever-married women of reproductive age (15-49) suffered primary or secondary subfertility (Hammarberg & Kirkman 2013; Rutstein & Iqbal 2004). However, the silence surrounding infertility and the scarcity of fertility treatment centres in resource-poor countries is resounding and is often rationalised in terms of population control, limited healthcare resources and the burden of other life threatening diseases (Inhorn & Birenbaum-Carmel 2008). This silence may reflect a eugenic position that views infertile poor people as being unworthy of treatment because overcoming infertility contradicts Western interests in global population control (Inhorn & Birenbaum-Carmel 2008; Greenhalgh 1995). Additionally, it is likely that religious and cultural proscriptions that render infertility as taboo or stigmatised serves to conceal the full extent of the problem (Dyer et al. 2004). For instance, in Tanzania, evil forces are thought to cause infertility (Gijsels et al. 2001). As the fertility of the immigrant generation often declines with duration of residence, minority women usually have a lower fertility than counterparts in their countries of origin (Coleman & Dubac 2010). Furthermore, the generation born in the country of resettlement often have lower fertility than that of the generation born in their country of origin (Coleman & Dubac 2010). As fecundity is generally greater in Africa, there is a possibility that women of African origin may find it more difficult to discuss their infertility problems within their communities and may internalise their problems (Tiu et al. 2018; Coleman & Dubac 2010; Awoyinka & Ohaeri 2014). This may have psychological consequences. Although some infertility studies have highlighted no significant differences between individuals from the general population and IVF patients, authors suggest this may be attributed to the ‘healthy patient effect’ in which those selected for fertility treatment tend to be physically and mentally healthy (Shani et al. 2016; Biringer et al. 2015; Yli-Kuha et al. 2010; Eugster & Vingerhoets 1999; Greil 1997; Venn et al. 2001). Research suggests that it is possible women undergoing IVF may possibly feel increased pressure to underreport socially stigmatised conditions such as mental illness (Shani et al. 2016; Lewis et al. 2013). However, despite the Human Fertilisation & Embryology Authority’s (HFEA) own evidence suggesting that African and Caribbean women are disadvantaged in accessing infertility treatment services, the regulatory body calls for ethnic minority communities to ‘speak out to get the fertility services they want’ (Jones 2013; HFEA 2006).

1.2.2 Barriers to Treatment and Ethnicity

It is important to highlight here that generalising these diverse communities into one homogenous group is problematised by the complex intersectionality of their identities. These intersecting ‘sites of oppression’ which include their economic, sexual, marital, citizenship and residential statuses as well as their linguistic, cultural and religious backgrounds further affect their ability to access treatment (Sillman et al. 2004). For this reason, recognition of how cultural, political, structural and economic constraints may affect their reproductive rights as

well as the extent of access to health care may be important. For example, although a North American survey comparing the perceived quality of the marital relationships of infertile couples who achieved pregnancy illustrated method of conception was inconsequential, it is important to highlight the study population was made up of mostly Caucasian, well educated and high income respondents (Cebert et al. 2019). It was suggested the similarity between the marital-role quality of women who had conceived with and without ART was the result of protective factors and resources which promoted resilience and resistance against the negative effects of major life changes (Weine 2016). Furthermore, as the duration of subfertility (or subfertility with the intent to have a child), rather than age, has been linked to psychological stress, including women pre, peri and menopausal women of all ages in the analysis may also be important (British Fertility Society 2020; Greil et al. 2011).

Therefore, in a society in which race and class inequalities are embedded, the impact of increasing ossification of public services, employment and social mobility resultantly has a significant effect on Black African women. This is because prevailing beliefs shape public policy and practice around the desires, needs and reproductive capacities of Black African women. In other words the social context in which African women in Europe potentially reproduce, is politically fraught as racialised discourse of their alleged aberrant motherhood erodes their full reproductive freedoms and rights (Jones 2013). Although a survey released by HFEA in 2018 revealed that 19% of women accessing infertility treatment were Asian, Mixed, African or Caribbean, just 1.9% and 0.4% were of African and Caribbean descent respectively (HFEA 2018). This is in contrast to 55.6% and 2.1% of those identifying as White British and Irish respectively (HFEA 2018).

For this reason, appreciating how the historical function of race may add to the contemporary reproductive experiences of nulliparous and primiparous women whose bodies not only continue to remain sites in the exercise of state power but the subject of stigmatisation within African communities may be vital. Empirical evidence suggests that psychological strain incurred by the mismatch between expectation and the (short lived) reality of motherhood may be pronounced in Black women who suffer significantly high rates of spontaneous abortion after ART (Maalouf et al. 2016; McQueen et al. 2015). As poor treatment outcomes for Black women increase their risk of chronic depression, it is possible that racialised disparities in their reproductive choices, health and care may be a source of traumatic stress that affects their psychological risk profile. This finding suggests that long term mental health may be a useful marker of success in addressing existing treatment and outcome inequalities. It is also indicative of the imminent need to frame the relationship between these racialised disparities and the long term psychological effect of ART on subfertile African women within a broader context. Furthermore, from the 1980s onwards, as market models gained more influence on the provision of health care, further repositioning of the patient resulted in conflict between the individual and collective views of the patient. It appears that individual patient choice has edged out collective patient voice. Although the demands of the individual patient may be irreconcilable with all patients, whether there is enough shared similarity between them to allow the merging of subgroups under a broad category is an open question (Mold 2013). For this reason, exploring how different ethnicities of subfertile women across Europe and Africa define quality care when evaluating their ability to access treatment may be important.

1.3 Why this topic is important: The questions address a gap in the literature

As fecundity is generally greater in Africa, there is a possibility that women belonging to these ethnicities will find it more difficult to discuss infertility issues within their communities (Aiyenigba et al. 2019; Coleman & Dubai 2010). Internalising their problems may have psychological consequences. Additionally, there is a possibility that subfertile African women may be relatively 'invisible' to policy makers and conventional demographic perspectives on fertility within the UK (Upton 2001). This dissertation will question whether these patients perceive that they receive an appropriate level of care that tailors fertility treatment around their position in a racialised society or their specific experience as an African woman in their community. This is important as it has been reported that non-representative samples, a failure to study culturally distinct populations and little regard for the 'social

construction of fertility' characterise literature specifically focused on infertility (Greil et al. 2010). Additionally, as many studies have suggested immigrant women are at a higher risk of mental illness than those who are non-immigrant, there is a possibility that migrant women in Europe may be at greater risk of suicide (Forte et al. 2018; Falah-Hassani et al. 2015). In this way, this review aims to highlight the issues that arise from pooling different ethnicities under wide categories and avoid failing to reach saturation⁴. Hence, the main aim of this study is to explore how socio-cultural factors, structural racism and ability to access ART among subfertile women across Africa and Europe might differ and whether there is a difference in their risk of developing mental illness.

The objective is to build on earlier needs assessment and priority setting exercises by the British Fertility Society, which is an organisation registered as a society in the United Kingdom, dedicated to strengthening decision making in the fertility treatment sector through the use of reliable and robust evidence (British Fertility Society 2020; Mahey et al. 2018; Harper et al. 2017). A qualitative systematic review exploring the meaning different ethnicities of subfertile women across Africa and Europe attach to care using their own words, rather than predefined concepts, may provide richer definitions that can be incorporated into practice and policy to resolve perceived barriers and improve their access to ART. For this reason, the identification and selection of papers will be determined mainly by the perceived care different groups receive rather than pre-defined concepts and standards in order to gain a broad understanding of how this issue impacts women in different places. The purpose of this would be to surmise the benefit of using either a patient-centred or a globally recognised definition to understand how different ethnicities of subfertile women across Europe and Africa define quality care when evaluating their ability to access treatment.

1.4 Care and Quality of Care: Definitions

The move away from assessing costs and activity to assessing quality with an emphasis on the efficient use of resources has led to an emphasis on quality improvement and performance measurement in the NHS and the development of a national performance framework (Campbell et al. 2000; NHS Executive 1999; Department of Health 1997). Although the definitions of care are varied and contested, the aspects of care that will be explored in this review will focus around the actions taken within healthcare systems to improve health and wellbeing (Campbell et al. 2000) (Appendix B Table 2.0). However, although systems and processes are important, their effectiveness in delivering quality care for individuals is dependent on users receiving the care they need (Campbell et al. 2000). In this review the requirements for care are also conceptualised as 'needs'.

Different stakeholders (patients, professionals and payers) perceive and define quality differently as what constitutes a desired outcome or process differs between them (Campbell et al. 2000; Annandale & Hunt 1998; McGlynn 1997; Blumenthal 1996; Joss & Kogan 1995; RCGP 1994). For instance, cost effectiveness and efficiency are of importance to managers as these factors reflect a societal perspective which prioritises the health needs affecting most of the population in a system with resource constraints, whereas service users consider patient-centred values such as humanness (Campbell et al. 2000; Wensing et al. 1994; Birch & Gafni 1992). Additionally, research highlights that the implementation of patient-centred care is related to higher quality of life (QoL), lower anxiety, depression and potentially improved treatment success rates (Gameiro et al. 2013; Aarts et al. 2012b). As healthcare services strive to meet individual and population level health requirements whilst maximising the efficiency of finite resources, the potential cost saving implications that can be achieved by mobilising resources according to need is increasing the growing importance of the concept of 'needs' (Asadi-Lari & Gray 2005). Designing services according to need is essential to providing patient-centred care and to improving their quality of care (Asadi-Lari et al. 2004). Linked to the development of needs based healthcare

⁴ Saturation is defined as the point at which a researcher may be reasonably assured that further data collection would yield similar results and thus confirm themes and conclusions that arose (Faulkner & Trotter 2017). Please note, a number of ethnic groups may be under-represented to generate a conclusion that may be applicable to all African and Caribbean communities.

services is the active involvement of patients and members of the public in service design and intervention development. For example, NICE (2007) recommended a 'needs assessment' of the target population should underpin behaviour change interventions to identify which behaviours require targeting and why and to assess the potential barriers requiring change. Understanding a patient's needs is thus suggested to be a crucial component of intervention design (NIHR 2014; MRC 2008; NICE 2007). Therefore, the meaning respondents attach to quality will be considered important components alongside their ability to access health structures and required processes of care (Appendix B Table 2.0) (Campbell et al. 2000). Of the two dimensions of care (access and effectiveness), access will be focused upon.

1.5 How will quality of care be explored in this review?

Quality may be measured using quantitative data collection method, such as surveys. However, when administering questionnaires to different groups of women with different cultural backgrounds, there is the possibility of different interpretations or understanding of the featured questions. In this way, particular groups may be more disadvantaged because using a protocol that is considered 'objective' potentially compounds existing inequalities or inequities between groups. Therefore, although studies using open-ended survey questions that do not include leading questions may be insightful, it is unlikely to add useful information that has not already been explored in studies that have incorporated interviews, focus groups and observational techniques in their study design. Systematic reviews of qualitative research draw together study findings, allowing a greater level of theoretical or conceptual understanding that can be gained by looking at an individual study in isolation (Campbell et al. 2003; Britten et al. 2002). For these reasons, it may be more beneficial to limit this to a systematic review using qualitative data. Qualitative research is an umbrella term that refers to various methodologies that include ethnography, phenomenology, action research, grounded theory and discourse analysis which use visual and/ or textual rather than numerical values to investigate perspectives of phenomena (Williams et al. 2020). Qualitative synthesis aims to go beyond a descriptive summary or aggregation of study findings and create an overall interpretation of the literature. The different methods of data collection include interviewing, focus groups and observation (Appendix C Table 3.0) (Williams et al. 2020). Focusing on one sort of critical appraisal and synthesising one sort of evidence is more feasible due to my limited resources. The thematic analysis will then be used to synthesise findings generated by the individual studies into descriptive and analytical themes which summarise and interpret study findings in relation to the research question respectively (Campbell et al. 2003; Britten et al. 2002). This review will also focus on care received from formal institutional health care systems and indigenous treatment which individuals have chosen to access. However, as care for individuals must be placed within the context of providing health care for the population, applying their concepts of 'access' to a set of performance indicators designed to reflect the opportunity cost of providing care for an individual or group of UK patients may be important. (Appendix B Table 2.0) (Campbell et al. 2000). Therefore, incorporating both global and patient-centred meanings of the quality of care may be beneficial as it may allow a framework enabling a better understanding of the meaning of the indicators and the aspects of care that may not have been covered nationally.

1.6 The Aims and the Objectives of the Review

1.6.1 Aim

Are the barriers to accessing ART and the perceived experiences of care between different ethnicities of subfertile women similar across Africa and Europe?

1.6.2 Objectives

1. Assess the quality and availability of the evidence on access to treatment in subfertile women of different ethnicity in different countries across Africa and Europe.

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2. Explore whether literature suggests there are factors associated with lower access to fertility treatment in subfertile women of different ethnicities across Africa and Europe and synthesise potential evidence: Summarise and interpret qualitative results.
 3. Provide recommendations for practice, policy and future research on factors associated with access to fertility treatment in subfertile women of different ethnicities across Africa and Europe.

1.6.3 Data Collection Methods

The most common qualitative research method, interview, can be either semi-structured, structured or in-depth and can explore patient experience in greater detail than a questionnaire (Appendix C Table 3.0) (Jamshed 2014). In-person face-to-face is considered the gold standard of interviewing in qualitative research (McCoyd & Kerson 2006). Additionally, interviews may be more inclusive and less discriminatory of illiterate participants as being able to explain the rationale of the study in their native language reduces cultural-linguistic filters and enables informed consent to be obtained (Culley et al. 2007). This suggests questionnaire studies, which tend to include fixed questions with little or no chance to follow-up or enquire whether respondents have understood the question, may have a higher probability of its results differing from that of interviews, focus groups or ethnographic studies. For this reason the inclusion of even an open-ended questionnaire method may not contribute to the understanding of this phenomenon in this review.

Focus group discussions are sometimes seen as being synonymous with semi-structured interviews because both techniques relate to their tendency to uncover the perception and values of a target population (Nyumba et al. 2018; Parker & Tritter 2006; Sewell 1997; Skeggs 1997; Mac an Ghaill 1994; Lacey 1970; Hargreaves 1967). Additionally, focus groups reduce the anxieties and pressures that one-to-one interviews can produce (Culley et al. 2007). Furthermore, unlike quantitative methods such as questionnaires, the potential for focus groups to address possible power relations in the research process and during ART may be far greater as they allow participants to raise issues they deem significant in a supportive forum (Appendix C Table 3.0) (Culley et al. 2007).

Ethnographies of IVF rely on the collection and analysis of patient observations which is then supplemented by background documentary research⁵ (Franklin 2013). This is to help understand social norms, the health system, current fertility treatment and assist in the development of a sociopolitical framework to appreciate the topic. For an ethnographer, a hypothesis is not a precursor to findings - rather, it can be the finding (Franklin 2013). This method is beneficial because it can venture into areas that might be have been overlooked and thus be a rich and in-depth source of information. This is a quality lacking in quantitative methods.

Although patient experience is increasingly considered an important dimension of assessing care quality, self-reported measures of patient experience are affected by demographic, socio-cultural and socio-economic factors (Kim et al. 2018). Given the potential challenge African women face within their social environment, it is possible that their psychological risk profile may be impacted by social context as well as biological factors. For this reason, the aim of this study is to review qualitative research with a systematic approach to identify similarities and differences in the experiences between different ethnicities of subfertile women accessing ART across Africa and Europe. Qualitative analysis is the approach of choice where the goal is to explore and present a thorough insight into the perceived quality of care or barriers of access to ART across specific cultures to an unfamiliar audience. Once findings are collated and themes are identified, the results will be summarised and their implications for practice, policy and research may be discussed. As a result, critical recommendations for future research that

⁵ This may include anthropology reference databases; encyclopaedias; dictionaries; handbooks; secondary data (reports and pamphlets on infertility and gender published by government and non-governmental organisations) or other anthropologically related resources, as well as interviews and possibly focus groups

broaden their access and improve their experience and reduce chronic mental health issues and health inequalities can be made.

2.0 METHODS

The methods employed in this systematic review closely (as was practical) adhered to the guidance given by the Cochrane Collaboration and conformed to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) recommendations (Appendix L Table 12.0).

2.1 Search Strategy

The aim of the literature search was to ensure the identification of relevant articles and exclusion of irrelevant ones for a defined research question (Shaw et al. 2004). Evaluation of search strategies was based on the extent to which relevant literature is identified (recall), a property akin to the sensitivity of a screening test (Shaw et al. 2004). Strategies may also be assessed by relevancy (precision), a property that may be likened to positive predictive value of a screening test (Shaw et al. 2004; O'Rourke et al. 1999). The recall and precision of three electronic search strategies, using thesaurus, free-text and broad-based terms, will be explored to identify the best approach to use in this review (Appendix D Table 4.0).

Searches were conducted from 1978, when IVF was introduced to the public and onwards. Electronic bibliographic databases such as EMBASE; MEDLINE; ASSIA; ERIC; CINAHL and Pubmed representing the disciplines of medicine, nursing and social sciences were searched. Peer-reviewed fertility journals including the International Journal of Fertility and Human Fertility were also searched.

Additionally, when including ethnicity in the search, it was important to be as comprehensive as possible. Although it would have been ideal to look for every country in Africa, a search for 54 countries was unfeasible. Therefore, a search for “African”, “Caribbean”, “ethnic minorities” and “immigrants” was carried out. It also included countries such as Ghana, Egypt, Nigeria and South Africa which have the highest number of registered IVF units in Africa and where it was likely many studies had been conducted (Ombelet & Onofre 2019). Furthermore, although this review intended not to restrict comparisons to race, “Black” was included in the search as this may be a common term used in studies. Also included were countries with the highest populations of foreign-born (African and Caribbean) population (Appendix E Table 5.0). Furthermore, countries such as France, Portugal, Belgium, Germany, Spain, Italy, The Netherlands and Sweden which have a similar healthcare system as the UK as well as a history of colonialism will also be included in the search (Weber 2018; Jalata 2011). Furthermore, although subfertility is the term used to describe this phenomenon, similar terms used to describe it such as infertility were also included to ensure studies were not missed.

As empirical evidence of the qualitative search strategies (thesaurus, free-text and broad-based) found that leaning on one strategy can potentially result in a loss of relevant records, a wider search combining all three methods was implemented as it maximises recall (Appendix D Table 4.0) (Shaw et al. 2004). However, it is noteworthy that although studies highlight these strategies have poor precision, limited precision is an unavoidable trade-off for such a high recall strategy (Shaw et al. 2004). Researchers also suggest limitations during the abstract screening process is indicative of poor database indexing and abstract details for many qualitative studies (Shaw et al. 2004). Nevertheless, as studies suggest a search is more efficient and effective with explicit study design/ descriptors and where definitive terms are included (Shaw et al. 2004). A snowball sampling strategy in which reference lists of articles in a similar research area could be identified was also implemented (Pedro et al. 2018). This was undertaken because empirical evidence highlights that incorporation of such a combined search strategy (electronic

searching and manual searching of reference lists) results in high retrieval rates of eligible studies (Edwards et al. 2002). Furthermore, although some studies noted that approaching experts in the field is a resource-intensive process which produces negligible results, this strategy was employed because other studies highlight it is an opportunity to be directed towards elusive relevant studies including unpublished ones (Pearson et al. 2011; Edwards et al. 2002). For this reason, a combination of a thesaurus, free-text and broad-based term search strategy that built on a previous Cochrane systematic review in the area was performed using the combined keywords outlined in Appendix G Table 7.0 (Dancet et al. 2011). Empirical evidence highlights that carrying out a verification strategy produced by using the Boolean “NOT” with the sensitive search strategy outlined above is beneficial as it ensures no relevant records have been missed (Booth 2006). Therefore, this was also actioned.

2.2 Eligibility criteria

2.2.1 Population

Eligible papers were searched where the population studied included women who are clinically subfertile (in accordance with WHO guidelines) and at an age where they can access fertility treatment across Europe and Africa.

2.2.2 Phenomenon of interest

The phenomenon of interest is the perceived quality of care or barriers of access to fertility treatment across Europe and Africa. As the objective is to understand the perceived quality of care, studies were excluded where the primary outcome is the efficacy of the trialed treatment. This included randomised controlled trials, prospective, interventional and clinical studies. Although information on differences in treatment between subgroups from the studies were collected, inclusion of studies were not based on the type of fertility treatment method the patients received. The aim of this review was also to investigate the ways in which cultural and societal factors affects the mental health of different ethnicities of subfertile women. Differences in their perceived experiences may have been indicative of issues with access that were not considered by healthcare professionals and could have potentially led to differences in mental health issues. For this reason, a comparison between the perceived experiences of different ethnicities of women across Africa and Europe from their fertility diagnosis or start of fertility treatment in studies published after ART became available to the public (1978 onwards) were explored. Including studies where the experiences of the participants were questioned from the time of their diagnosis was chosen because studies report that it is the duration of subfertility that has been linked to psychological stress (Greil et al. 2011).

2.2.3 Exclusion criteria

- Ethnic status

Studies that provided no information on the ethnic status of women were not included to ensure the population included women of different ethnicities across Africa or Europe (Appendix G Table 7.0).

- Undefined or unique populations

Studies that did not share the experience of women who perceived they were subfertile across Africa and Europe or had not explored subfertility. Studies that included only the views of healthcare professionals were excluded.

- Study design

Quantitative studies (including randomised controlled trials, interventional and surveys) and reviews were excluded.

- Reviews and conference abstracts

Studies that did not present original data such as review articles were also excluded but their list of references were searched for original research studies that met inclusion criteria. Conference abstracts were also excluded because they provide insufficient details of methodology for critically appraisal.

- Language

Studies published in a language other than English were excluded due to limited resources (cost and time) for accurate translation.

2.2.4 Inclusion criteria

- Participants

Patients regardless of race, economic, marital, citizenship and residential status and from any linguistic, cultural and religious background across Africa and Europe were incorporated in this review (Appendix H Table 8.0).

- Countries

Women from African countries that have the highest number of registered IVF units in Africa, such as Ghana, Egypt, Nigeria and South Africa, were included in this review (Ombelet & Onofre 2019). Other countries such as Ireland, Kenya and South Africa that had high rates of out-migration to the UK at the time IVF was introduced were also included as their treatment experience may have differed from that of more recent migrants (ONS 2013; Cooper 1985). Also included were the countries with the highest populations of foreign-born (African and Caribbean) populations (Appendix E Table 5.0).

Furthermore, countries such as France, Portugal, Belgium, Germany, Spain, Italy, The Netherlands and Sweden which have a similar healthcare system as the UK as well as a history of colonialism will also be included in the review (Weber 2018; Jalata 2011).

- Previous treatment

Women who were on consecutive fertility treatment rounds were included. This is because, in some cultures the birth of one child results in stigmatisation. As a result of feeling greater pressure to have more children and undergo treatment, they may suffer or present with mental health issues.

- Age

The age at which women can access publicly financed IVF coverage varies across Europe (Appendix I), whereas support for fertility treatment is difficult regardless of age in Africa (Ombelet & Onofre 2019; Osei 2016). As women can access infertility treatment in Europe free of charge up until age of 40 on average, the inclusion of premenopausal women (18-35 year olds) who have also accessed these services was also important. Studies report that it is the duration of subfertility (or subfertility with the intent to have a child) that has been linked to psychological stress (Greil et al. 2011). For this reason it may be possible that perimenopausal or menopausal women who access infertility treatment later on in life may be better prepared against a prospective loss of childbearing years if their intention to have a child was of a comparatively shorter duration. As younger women are just as susceptible as their older counterparts to developing mental health issue, their inclusion may also be important.

- Marriage status

Furthermore, as those in heterosexual partnerships represents 91% of those seeking treatment in the UK, it is possible that the needs of those without partners are not prioritised (HFEA 2019). For this reason, those who were not in a relationship were included in this review.

- Publication date

Older publications (from 1978 up to 2020) were eligible for inclusion as the aim is to capture any change in experiences over time. For example, changes in patient autonomy, political climate and migratory patterns across Africa and Europe may further exacerbate the mental health of already vulnerable groups, particularly those who are Black African (Apslund 2019; Forte et al. 2018; Mold 2013; Lindert et al. 2009). The cut off date for including studies in this review was 31 March 2020.

- Data collection methods of studies

Studies were qualitative methods (including interviews, grounded theory, phenomenology, focus groups, participant observation and ethnography) were included.

- Follow-up studies

Follow up qualitative studies were included as they may highlight pertinent issues. Quantitative longitudinal studies such as cohort studies will be excluded. For example, observing whether any differences may exist between different ethnicities of subfertile women over a longer time period may be important. For instance, if there is varying access to psychological support among different ethnicities of women following unsuccessful attempts to conceive and different degrees of access to alternative childrearing options, such as adoption or fostering is experienced, their risk of developing mental health issues may vary.

2.2.5 Data Management and Study Selection Process

The screening was completed in two stages. The electronic search strategy was checked with my personal tutor and the college librarian before it is conducted. Additionally, data will be extracted systematically in a data extraction form adapted from one designed to record clinical intervention data to one capturing qualitative data such as patient experience of care and barriers faced when accessing fertility treatment (Appendix M). After removing duplicates manually or using the duplicate function of Endnote X7.5, the title and abstract of all identified studies from the search will be exported into Excel and inspected. At this stage, studies will be categorised as 'INCLUDE', 'EXCLUDE' or 'MAYBE'. Those that do not meet the inclusion criteria will be excluded. Full text articles attained for all studies will be defined as 'INCLUDE' or 'MAYBE'. The author will include information available from the publications and may seek additional information by contacting primary authors. Reasons for further exclusions following full-text review will be documented. The selection process, including search results and reasons for exclusion at each stage of screening, will be presented in a PRISMA flow diagram.

2.3 Critical Appraisal of the Literature

In order to assess the quality of the studies contributing data to this review, a critical appraisal tool is required (Munthe-Kaas et al. 2019). In health science fields, there has been widespread acceptance of the utilisation of tools to critically appraise studies and a shift in academic debate from 'whether or not to make an appraisal to what criteria to use' (Munthe-Kaas et al. 2019; Hannes & Macaitis 2012). For this reason, it is desirable to critically appraise the methodological strengths and limitations of the methods applied within the studies in this review. This is because omitting such a crucial element of evidence-based healthcare may potentially weaken the case that qualitative research is as integral to evidence-based healthcare as quantitative research (Williams et al. 2020). The two types of critical appraisal approaches for qualitative research are checklists or frameworks. A robust quality

appraisal tool can draw on the strength of current frameworks and checklists whilst assessing the research design (sampling/ data collection/ analysis) and the degree of rigour or trustworthiness (transferability, credibility, reflexivity and dependability) of a research method (Williams et al. 2020). However, some tools, such as the CASP Qualitative Checklist (Critical Appraisal Skills Programme), have more insights regarding its strengths and limitations than other tools (Majid & Vanstone 2018; Critical Appraisal Skills Programme 2016; Dixon-Woods et al. 2007). For instance, a study comparing methods of appraisal for qualitative research papers that were candidates for inclusion in a systematic review of support for breast-feeding highlighted that reviewers were sensitised to the procedural aspects of research (Dixon-Woods et al. 2007). The deficiencies of compliance with the expectations of research practice compared to two other appraisal methods, a unprompted judgement based on expert opinion and UK Cabinet Office quality framework (QF) were also highlighted (Dixon-Woods et al. 2007). Unlike QF which is universal criticised for its length, complexity and laboriousness, CASP was not deemed frustrating to use (Dixon-Woods et al. 2007). Although it is possible a different review question may have resulted in different outcomes and the use of CASP may not be a straightforward solution, as it is likely the credibility and contribution of selected papers for the synthesis may be more reliable using CASP, it is a more appropriate tool to use ((Dixon-Woods et al. 2007).

Using a tool that is brief is advantageous for application in health care and policy evaluations that require an efficient translation of evidence (Majid & Vanstone 2018). Additionally, as comprehensive tools require a significant investment of time from multiple researchers with extensive qualitative methodology expertise, their use in this review may not be beneficial (Majid & Vanstone 2018). A recent compendium of appraisal tools highlighted how shorter appraisal checklist tools such as CASP, JBI (Joanna Briggs Institute) and Popay enable efficient evaluation of qualitative research (Majid & Vanstone 2018; Joanna Briggs Institute 2016; Belgrave et al. 2002; Popay et al. 1998). However, concern was raised regarding the limited information on the development as well as the application of guidelines of Popay (Majid & Vanstone 2018). Questions regarding the use of an appraisal checklist have also highlighted whether they simply assess the quality of methodological reporting rather than the design and execution of the study (Majid & Vanstone 2018; Goldsmith et al. 2007). For example, CASP may focus on on how studies are reported in journals rather than rigour (Majid & Vanstone 2018). Similarly, some tools, such as the JBI may assess the conduct of research studies, that do not explicitly express their philosophical orientation, as being of lower quality rather than acknowledge the content of studies may be a reflection of reporting choices (Majid & Vanstone 2018). This discovery is relevant because descriptive qualitative research, that focuses on salient, common or conceptually powerful qualitative findings, may be the most relevant for health policy because this design may be more useful representing patient perspectives (Majid & Vanstone 2018). For this reason, using a tool that focuses on theoretically dense qualitative articles over others would be counterproductive. This is especially the case for a review that aims to synthesise the best available evidence and requires the inclusion of such descriptive research that would otherwise be dismissed or de-emphasised (Majid & Vanstone 2018). Additionally, ascertaining implicit philosophical assumptions is time consuming and requires a reviewer who has knowledge and experience of the philosophical foundations of qualitative research (Majid & Vanstone 2018). CASP, in contrary to JBI, places less importance on such characteristics (Majid & Vanstone 2018).

Reflexivity refers to the extent that a researcher demonstrates awareness of how they may have influenced the research process (Majid & Vanstone 2018). A mismatch between the requirements of reflexivity in the tool guidelines and the limits of what can be reported about it in a research study may mean that studies that operationalise it in a way that is incongruent to the appraisal tool may receive a negative assessment (Majid & Vanstone 2018). Additionally, the phrasing of the guidelines in some tools, such as the Evaluation Tool for Qualitative Studies, ETQS (Long & Godfrey 2004), frames all reflexive thinking as ‘bias’ (Majid & Vanstone 2018). This implies there is an assumption that the views of an investigator would adversely influence rather than supplement the final interpretation and synthesis (Majid & Vanstone 2018). Therefore, in conclusion, an appraisal

from the CASP tool will be used in this review to assess the extent to which the research design and research methods of included studies are transferable, reflexive and dependable. This may potentially be a better tool to ensure the inclusion of data from an ethnically diverse group of subfertile women across Africa and Europe in this review. The selection of CASP is based on the objectives, expertise, time and resources available to the reviewer.

2.4 Data Extraction

Prior to synthesis, details about study design, participants (number and characteristics) and study context (timing, location, experience, severity of mental illness and other conditions) was independently extracted into a data extraction form in Microsoft Word. The findings from each paper (views of the participant and author interpretation of findings) were extracted verbatim from the abstract, results and discussion and imported on to the same template.

2.5 Thematic Synthesis

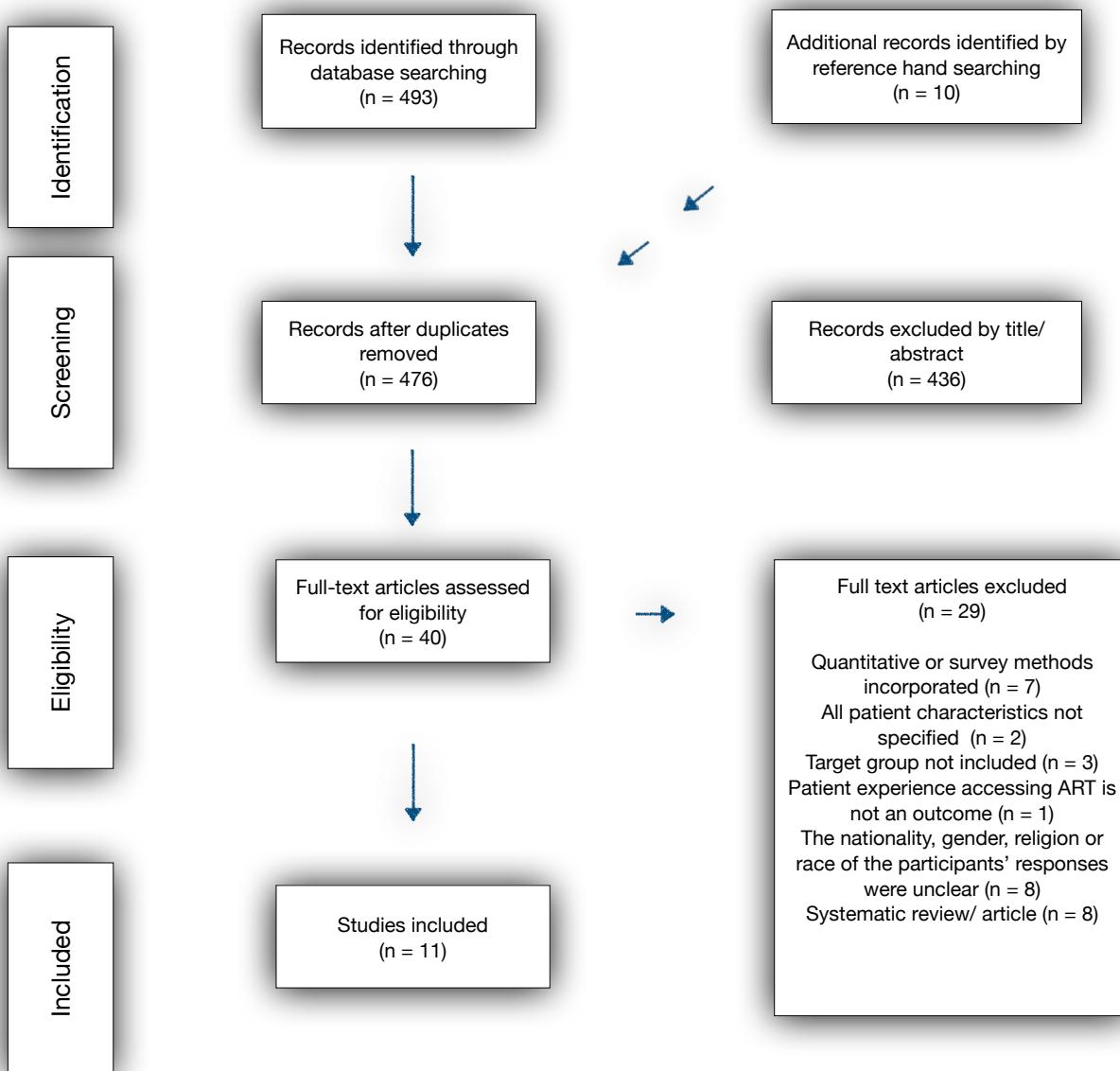
Thematic synthesis will bring together the findings of the individual studies in the review (Thomas & Harden 2008). Thematic synthesis is based on the principles of thematic analysis of primary data. It is composed of three stages. The first consisted of line by line coding of relevant text. This involved systematically reviewing all data within the abstract, results and discussion sections of the study and assigning codes to sections of text that represents meaning and context. The second stage of synthesis was composed of developing descriptive themes from the initial codes formed. This involved the comparison and categorisation of codes and categorising according to their similarity and difference with the intention of creating a set of descriptive themes that represented the content and meaning of every individual study included. The third stage of synthesis involved the generation of analytic themes which build on descriptive themes (Thomas & Harden 2008). This involved the application of the researcher's interpretation and understanding of the data and going beyond the presented conclusions of the original author.

3.0 RESULTS

3.1 Search result and study selection

476 studies at the title and abstract stage from a total of 493 identified in the search were screened (Figure I). Of these, 40 were reviewed at the full text stage and a further 24 excluded, leaving a total of 16 included studies. The most common reason for excluding studies at the full text stage included a lack of clarity related to nationality, gender, religion or race of the participants or being a systematic review or article ($n = 11$). The search terms used generated a total of 493 references from CINAHL, Scopus, ERIC, ASSIA, MEDLINE, EMBASE and Pubmed databases. A further 10 records were found through a hand search reference list. After the removal of duplicates, 476 remained. A first screen by title removed 40 studies and a further 440 studies were excluded after abstract screening. 40 articles were then selected for full text review. After applying the pre-defined inclusion criteria, 29 of these articles were excluded. 11 studies were selected for the final review (Dierickx et al. 2019, Dierickx et al. 2018, Bailey et al. 2017, Fledderjohan 2012, Roudsari & Allan 2011, Weinger 2009, Mogobe 2005, Mariano 2004, Hollis 2003, Hebei 2000 and Gerrits 1997). No grey data met the inclusion criteria (see Figure I). The list of excluded studies at full text review can be found in Appendix F Table 6.0.

Figure I: Study selection flowchart (adapted from PRISMA 2009 flow diagram)



3.2 Study characteristics

Eleven studies were finally included in this review, which are referred to first author and year of publication. The characteristics of the studies can be found in Table I and Table II. The tables are organised alphabetically by study author.

Table I: Characteristics I

First Author and Year	Study Design and Setting	Study dates	Study Objective	Ethnic origin of participants and sample size
Dierickx et al. (2019)	Method of data collection: Interview, informal conversations and group discussions Method of analysis: Thematic analysis Setting: Community (rural and urban communities in The Gambia)	2017 - 2018	Understand the health seeking behaviour of women with infertility and the influence of etiological beliefs on health seeking paths	Mandinka, Jola and Karonika (participants were from The Gambia and Senegal) Size: 36
Dierickx et al. (2018)	Method of data collection: Interviews, group discussions and participant observation with informal conversation Method of analysis: Thematic analysis Setting: Urbanised region of The Gambia	2017 - 2018	Understand the implications of infertility in urban Gambian communities; examine how this relates to cultural practices	Mandinka, Fula, Masiwanka, Wolof, Serer, Aku and Karonika (The Gambia) Size: 33
Bailey et al. (2017)	Method of data collection: Semi-structured interview) Method of analysis: Grounded theory Setting: Community, Unstated (UK)	Unstated	To provide a model of resilience among women undergoing fertility treatments, who experience repeated unsuccessful conception attempts	British, Latvian and mixed British and Asian Size: 11

First Author and Year	Study Design and Setting	Study dates	Study Objective	Ethnic origin of participants and sample size
Fledderjohann (2012)	<p>Descriptive qualitative study: Semi-structured interviews</p> <p>Setting: Secondary care (four health clinics (with an emphasis on gynaecology and obstetrics outpatients, Ghana))</p>	2008	Explore the implications of infertility in Ghana	<p>Ghanaian</p> <p>Size: 107</p>
Weinger (2009)	<p>Method of data collection: Descriptive qualitative study, Structured in-depth interviews</p> <p>Method of analysis: Thematic analysis</p> <p>Setting: Community (Interviewer apartment, Cameroon)</p>	Unstated	Examine Cameroonian coping measures for childlessness and the subsequent social marginalisation experienced	<p>Cameroonian</p> <p>Size: 5 interviewed (out of 10 approached)</p>
Magobe (2005)	<p>Method of data collection: Unstructured interview (open ended questions)</p> <p>Method of analysis: Interpretative phenomenological analysis</p> <p>Setting: Community (rural communities, Gaborone, Botswana)</p>	Apr - Sep 1997	Explore the meaning of infertility and describe how women felt that their spouses, friends and relatives influence this; delineate the processes and strategies used by women in dealing with infertility	<p>Botswana</p> <p>Size: 40</p>

First Author and Year	Study Design and Setting	Study dates	Study Objective	Ethnic origin of participants and sample size
Roberts & Franklin (2004)	<p>Method of data collection: Semi-structured, formal and informal interviews and participant observations</p> <p>Method of analysis: Thematic analysis</p> <p>Setting: Respondent's home</p>	Feb 2001 - Aug 2003	Investigate how patients experience PGD and how it fits into their lives, reproductive histories and futures?	British Size: 21
Mariano (2004)	<p>Method of data collection: Interview</p> <p>Method of analysis: Ethnography</p> <p>Setting: Community (rural communities in Mozambique)</p>	2001 - 2002	To understand the experiences of infertility in Shangana society, describe the ways in which people seek solutions and explore the individual and social implications of reproductive failure	Shangana (Mozambique) Size: 18
Hollos (2003)	<p>Method of data collection: Semi-structured interview</p> <p>Method of analysis: Ethnography</p> <p>Setting: Community (home, Ijaw community, Nigeria)</p>	2002	To illustrate how local meanings of infertility are shaped by the social and cultural context and how they influence the life experiences and coping behaviours of infertile women in an Ijo community in the Niger Delta	Ijo (Nigeria) Size: 6

First Author and Year	Study Design and Setting	Study dates	Study Objective	Ethnic origin of participants and sample size
Yebei (2000)	<p>Method of data collection: Exploratory in-depth interviews, informal discussions</p> <p>Method of analysis: Thematic analysis</p> <p>Setting: Community (home and workplace, Netherlands)</p>	1999	To determine the attitudes and needs of infertile Ghanaian women living in Amsterdam and examine barriers to ART access	Ghanaian Size: 12
Gerrits (1997)	<p>Method of data collection: Semi-structured interview and participatory observations</p> <p>Method of analysis: Interpretative phenomenological analysis</p> <p>Setting: Community (home, Mozambique)</p>	1993	Exploring the social and cultural aspects of infertility in Mozambique	Macua (Mozambique) Size: 34

Table II: Characteristics II

First Author and Year	Perceived Barriers/ Experiences of Quality of Care	Conclusions	Overall Quality
Dierickx et al. (2019)	<p>Women used both biomedical and indigenous treatment from local healers, sacred places and kanyaleng groups depending on: (i) Perceived aetiology of infertility; (ii) Perceived effectiveness of available treatment; (iii) Duration of the fertility problem; (iv) Affordability; (v) Accessibility (which was influenced heavily by SES if the biomedical health sector was being considered); (vi) Availability of treatment and (vii) respondents' family and social networks</p>	<p>Attributing delay, adherence and treatment choice to 'traditional' beliefs or lack of knowledge does not reflect the pragmatism behind infertile women's choices in their health seeking given the existing structural inequalities they experience. Health authorities should provide information, counselling on infertility prevention and treatment and develop health systems guidelines for infertility management</p>	M
Dierickx et al. (2018)	<p>Unable to conform to their gender role amidst a strong social pressure to procreate, infertile Gambian women were faced with: (i) financial problems; (ii) social stigma and (iii) emotional and physical violence in their marriage</p> <p>Although social positions and identities interact and influence behaviour, the financial implications, social stigmatisation, marital problems and emotional difficulties faced, all women reported feelings of trauma, stress and sadness</p>	<p>The capacity of the health system needs to be built to follow up and provide psychological support as well as prevent and treat fertility problems (targeting individuals with little financial and social resources)</p>	M
Bailey et al. (2017)	<p>Affordability and availability</p>	<p>Experiencing adversity led them to identify their resilient qualities through (i) recognising their own strength (ii) relying on strategies which helped them get through previous experiences of adversity and (iii) by taking control of their treatment.</p> <p>However, efforts to build themselves had emotional and practical costs.</p> <p>Clinicians should be mindful of the need to gain control over treatment by seeking other methods - particularly relevant among minority ethnic groups and those with less access to publicly funded health care</p>	M

First Author and Year	Perceived Barriers/ Experiences of Quality of Care	Conclusions	Overall Quality
Fledderjohann (2012)	<p>Women felt burdened with a disproportionate share of the blame for infertility and faced greater social consequences (ostracisation) than their partners. Familial and marital pressure to conceive resulted in emotional strain ranging from loneliness and worry to stress and depressive symptoms. Physical ailments ranging from headaches/body aches reported as reactions to ART</p>	<p>The findings suggest the consequences of infertility in Ghana are widespread and severe</p> <p>Although data limitations make it unclear whether infertile women are significantly more likely to experience physical ailments, authors report the study provides preliminary evidence of a link between infertility and physical health</p>	L
Weinger (2009)	<p>Childless women are banished from homes and required to return their bride price. Those not college educated face higher risk of severe poverty as marriage for many is an economic means for survival in this pronatalist and patriarchal society.</p> <p>Unable to produce biological heirs, they experience social rejection and are branded as deviants whose value is related to their reproductive function on behalf of men</p>	<p>As childlessness is a threat to Cameroonian women's survival, the provision of specific economic support and opportunities for these women as well as increased access to adequate reproductive health services.</p> <p>Community education, places of worship and support networks may help people understand the medical reasons for infertility (poor access to fertility clinics, lack of prenatal care, proper delivery conditions and treatment for STDs as well as safer abortion procedures) and alleviate shaming and loneliness</p>	M
Magobe (2005)	<p>Women perceived infertility as denying of self to varying degrees within the social context of patriarchy: (i) denial of status as a woman; (ii) denial of economic and social security in old age and (iv) denial of immortality (Infertility sign of supernatural chastisement)</p>	<p>Women developed coping strategies including looking for deeper meaning, giving in to feelings, compromising, getting away from fertility related issues and pursuing adoption to protect themselves from emotional harm</p>	L
Roberts & Franklin (2004)	<p>Decisions about treatment factored in the financial and social costs. Patients considered personal and familial relationships and were concerned how they were perceived by society (due to PGD stigma)</p>	<p>It is uncertain the extent to which care delivery is sensitive to their burdens and during/ after treatment when they encounter challenges or difficult decisions - assistance identifying suitable coping strategies may help circumvent the development of potential long term effects</p>	M

First Author and Year	Perceived Barriers/ Experiences of Quality of Care	Conclusions	Overall Quality
Mariano (2004)	<p>Religiosity/ spirituality (punishing spirits inflict infertility due to deviation from the rules of patrilineal society); social exclusion from traditional ceremonies/ rituals and activities; marital instability</p> <p>Results in psychological/ emotional pain</p>	<p>Healers are their first or only line of therapeutic resort. Although patients are sent to the health centre for treatment if healers are not efficacious, good local ones are scarce and lack the services for women to 'release their pain' so they can overcome their emotional as well as physical suffering</p>	L
Hollos (2003)	<p>Social strain: Marital instability; marginalisation in the household and exclusion from community social activities and traditional ceremonies</p>	<p>Women developed coping mechanisms: (i) Biomedical and local remedies; (ii) risky behaviours to become pregnant; (iii) 'marry other women' to become an 'owner' of children; (iv) fostering; (v) feigning pregnancy/ miscarriage</p> <p>These strategies had psychological implications (depression, anxiety or stress)</p>	L
Yebel (2000)	<p>Poorer access and availability</p> <p>(i) Inter-cultural misunderstandings led women to misinterpret clinical decisions/ approach; (ii) Language barriers left Ghanaian women unable to access existing Dutch information materials; (iii) As Dutch national health policy prohibits ART at 40, availability was limited (iv) Stigmatisation for childlessness</p>	<p>Given the low success rates, more effort to understand how cultural differences among migrant populations may affect perspectives of the quality of fertility treatment is vital</p> <p>Although women saw adoption and fostering as temporary and unacceptable, more information in various languages on adoption and fostering in hospitals may better inform those willing to try it</p> <p>The range of factors associated with infertility must be better communicated due to the strong cultural belief that ovulation, irrespective of age, was a sign of fertility. The role of STDs also require better explanation (especially considering the possible occurrence of extramarital sex)</p>	M
Gerrits (1997)	<p>Infertility is perceived to originate from the acts of people, spirit or witches or natural causes</p> <p>Infertile women experience exclusion from social activities and traditional ceremonies; divorce; psychological distress</p>	<p>Infertile women apply various strategies to have a child: (i) treatment (via biomedical treatment centres and traditional healers); (ii) adultery and (iii) fostering</p> <p>Women suffer social exclusion and psychological distress. Infertility needs to be considered in a culturally sensitive way by policy and programme makers - improved interventions (beyond preventive measures) considering existing cultural practices and perceptions of patients re: quality of care is vital.</p>	L

Most of the studies were conducted in West Africa (n = 4) and Southern Africa (n = 3). Within West Africa, one study was conducted in Ghana, two in The Gambia and one in Nigeria. Within Southern Africa, two were conducted in Mozambique and one in Botswana. The remaining four were conducted in Cameroon, Central Africa (n = 1), The Netherlands, Europe (n = 1) and the UK, Europe (n = 2).

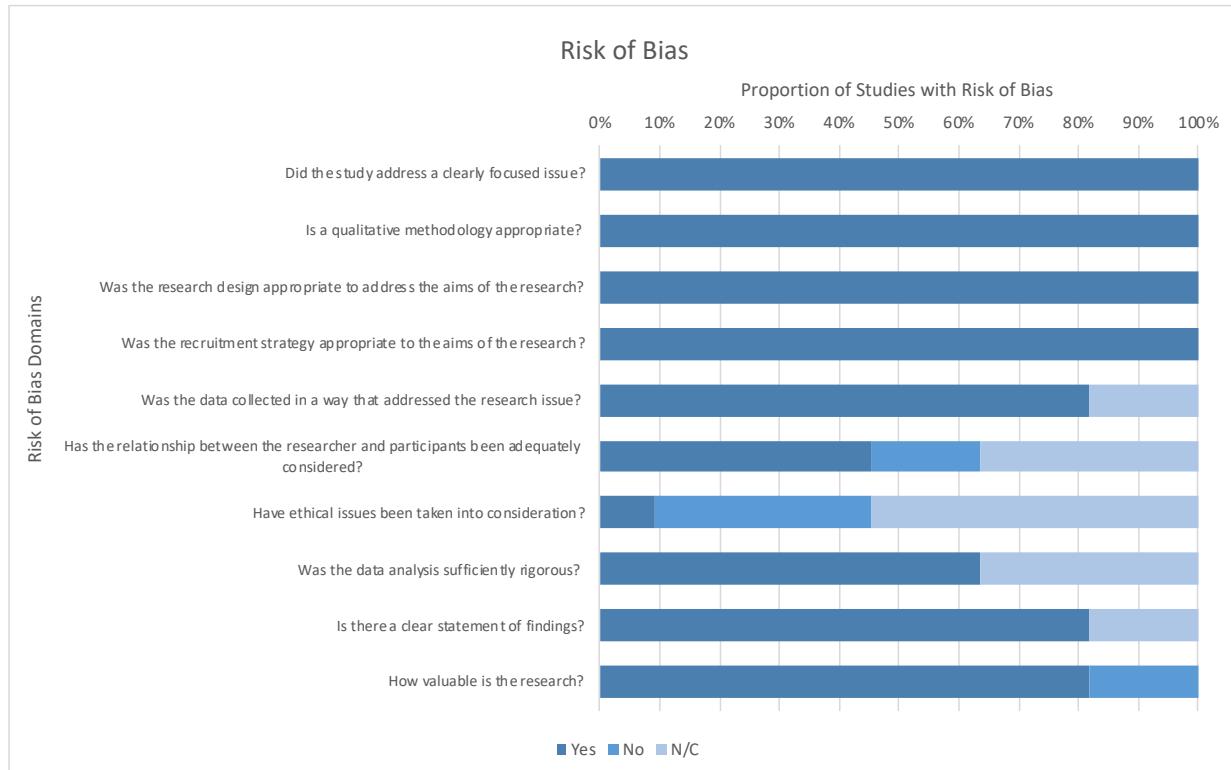
Four studies used semi-structured interviews (Gerrits 1997, Bailey et al. 2007, Hollos 2003, Fledderjohan 2012), one was an unstructured interview (Magobe 2005), one was a structured interview (Weinger 2009), one was described as an in-depth interview (Yebei 2000), one was an ethnography (Mariano 2004) and two involved a combination of interview, observation with informal conversation and group discussion (Dierickx et al. 2018, Dierickx et al. 2019). Three of the studies were conducted during the time periods 1993 to 1999 (Yebei 2000, Gerrits 1997, Mogobe 2005), five during 2001 to 2018 (Mariano 2004, Hollos 2003, Fledderjohan 2012, Dierickx et al. 2018, Dierickx et al. 2019) whilst the dates were unstated for two studies (Weinger 2009, Bailey et al. 2018).

As the standard epidemiological and demographical conceptualisations of infertility, subfertility, miscarriage and stillbirth were not always meaningful for people living in low- and middle-income countries, those who believed they were infertile (regardless of the duration of their fertility issues or number of living children) were included (Dierickx et al. 2019; Dierickx et al. 2018; Fledderjohann 2012; Weinger 2009; Mogobe 2005; Mariano 2004; Hollos 2003; Yebei 2000; Gerrits 1997). Eight of the studies implemented purposive sampling through hospitals where women sought gynaecological and obstetric services, community leaders and healers. Purposive sampling here was implemented to identify and select women particularly knowledgeable about infertility or subfertility, were available and willing to participate as well as capable of expressing their experiences expressively and reflectively (Palinkas et al. 2016; Cresswell & Plano Clark 2011). One study recruited consecutive women who considered themselves infertile from part of the population close to hand (Weinger 2009). The sampling method of one study was unstated (Hollos 2003). The number of infertile women included in each study varied from 5 to 107.

3.3 Critical Appraisal

Critical appraisal was carried out using the 'Critical Appraisal Skills Program' (CASP) tool for qualitative studies. Points were assigned to each indicator and an overall score was used to assess quality (Figure II).

Figure II: Risk of Bias



Five were 'low' quality and were conducted in Mozambique, Ghana, Nigeria and Botswana. Six were 'medium' quality and were conducted in Cameroon, UK, Amsterdam and The Gambia (Appendix K). Four of the five 'low' quality studies were earlier publications, perhaps reflecting changes in study reporting standards over time. None of the studies included scored the total of 10 points ('high' quality). All the studies failed or were not clear enough in taking into consideration ethical issues. It is not acknowledged how the effects of the study on the participants during and/ or after the study were handled. The studies which were deemed at high risk of bias had significant limitations relating to the critical examination of the role, potential bias and influence of the researcher during sample recruitment as well as data selection, collection and analysis. However, the effect of interpretative bias on analysis was explored in a Cameroonian study which highlighted the circumstances of the author's birth and privileged opportunities (Weinger 2009). The author suggested as she has mostly been in a position that enabled her to financially support herself, her ability to understand the need to conform to any pronatalist expectations to survive may have been limited. Additionally, unlike participants who are closely tied to communities where biological motherhood is a cultural imperative, the author lived in a mobile one where many people in her social and professional relationships were unaware of her (voluntary) childlessness. In this way, as her social location freed her from some of the heightened pressures experienced by Cameroonian women, she may not have fully understood the depth of their personal loss. Recognising this could be an issue, Weinger chose to include two Cameroonian colleagues (one who worked for the Ministry of Women Affairs and had counselled childless women) to avoid cultural biases, blindspots and lack of cultural familiarity that may have seeped into the data collection and analysis.

Furthermore, inadequate discussion of the selection process was also an issue. One study suggested that the inclination of both genders to conceal their fertility issues may have hampered the ability of the researcher to

discover and record cases that were relevant to the study (Mariano 2004). For example, female partners were primarily considered responsible for childlessness. Actions to alleviate this were unmentioned. The strength of the design of the studies was also limited by the use of one researcher and lack of critical discussion of the findings in relation to the literature (Fledderjohan 2012; Mariano 2004; Hollos 2003).

Also of concern was the transferability of findings discussed. One study highlighted that as participants need the time and monetary resources for treatment, it was likely that participants were likely to belong to a higher socioeconomic background than the average Ghanaian women in the population (Fledderjohan 2012). Thus the extent to which these findings are relevant to their poorer Ghanaian peers is questionable. The socioeconomic and religious diversity of the participants in the studies conducted by Mogobe (2005) and Gerrits (1997) were also unclear. As a result, it is unclear whether those most able to communicate their experiences of limited access to fertility treatment/ barriers to treatment were identified. This may have limited the breadth of understanding of the treatment process in the analysis. Two researchers questioned the generalisability of their findings and stated a larger random sample of infertile women would need to have been interviewed for this to be possible (Fledderjohan 2012; Hollos 2003). However, as generalisability is not often an objective for qualitative researchers, the ability of these researchers to generate the sort of sample enabling them to achieve this is questionable.

Additionally, age and the range of potential characteristics, such as psychiatric history, across a possibly heterogenous population was not described or analysed in sufficient detail. For example, these studies relied on volunteer participation. Although some women with fertility issues reported depressive symptoms such as worry, sadness and anxiety to suicide, it is possible women suffering with more severe symptoms may have made them less likely to take part. This would result in mental health issues being under reported in these studies and compromised transferability, as the audience is not given enough context and detail to determine whether their results apply to the wider population of subfertile African women in the two studies. Where the mental health of respondents were highlighted, medication, diagnoses, prior suicidal attempts were unmentioned. However, it is possible interviewees feared jeopardising being allowed to complete the interviews. Furthermore, age being unrecorded does not invalidate the study as in some African countries, age is not documented. Nevertheless, it is possible that investigators were able to make reasonable assumption of a participant's age.

There were also common themes in terms of domains at low risk of bias (Appendix K). The definition and classification of access to care used international guidelines, which was often clear and well defined, helped identify deficiencies in the reporting standards of the studies. Similarly, the meaning of subfertility is based on the diverse perspectives of women experiencing it who have expressed their understanding of it using their own language, rather than imposed clinical definitions. Therefore, although clinical definitions may have changed over time, using definitions that are also shaped by social and cultural context, results in an information-rich source highlighting the sociocultural barriers that subfertile women across Africa and Europe may experience (Palinkas et al. 2016; Cresswell & Plano Clark 2011; Patton 2002).

3.4 Findings of Included Studies: Perceived Quality of Care

The following section will explore the findings of included studies and will be organised to describe perceived quality of care respondents received (Table III). Free coding the findings of included studies produced meaningful segments of data that were grouped together according to similarity and new descriptive categories were created that captured the meaning of grouped free codes (Thomas & Harden 2008). For example, free codes that captured experiences relating to the ability to travel to treatment centres related to organisational factors affecting the structure of the healthcare system, were grouped to form the descriptive category, access. Initial codes related to perceived quality of healthcare were grouped into six categories (Table III).

Table III: Contents of the Findings of Included Studies

Perceived Quality of Care Themes	
Healthcare System (Structure)	3.4.1 Access
	3.4.2 Affordability
	3.4.3 Availability
Patient-Centred Care (Process)	3.4.4 Folk healing: Alternative and Complementary Therapies
	3.4.5 Beyond Technical Execution of Care: Dignity, Trust, Respect and Humanised Care
Acceptability of Care	3.4.6 Acceptability of Care

Under factors associated with the organisational structure of the healthcare system, these included 'Access', 'Affordability' and 'Availability'. Under factors related to patient-centred care (process), these included 'Folk healing: Alternative and Complementary Therapies' and 'Beyond Technical Execution of Care: Dignity, Trust, Respect and Humanised care'. Under factors connected to the consequences of care, was 'Acceptability of Care'. Whilst initial codes related to the perceived barriers of access to fertility treatment were grouped into two categories, religious and cultural proscriptions and strained social interactions (Table III). Meanings were refined and themes developed by reassessing the data contained within each category to create descriptive themes. For example, an overlap in experiences was seen between the emotions associated with shame and the strained social interactions that impede barriers of access to ART category. This developed into the descriptive theme, ostracisation and stigmatisation from the community. Based on the experiences described, analytical themes were developed which inferred and theorised about the experiences of different ethnicities of subfertile women accessing fertility treatment and the impact this may have on future intervention development (Figure III).

Table IV: Descriptive Themes: Perceived Quality of Care

Analytical Theme: Perceived Quality of Care	Descriptive Theme: Perceived Quality of Care	Summary of Findings	Illustrative Quote(s)
Structure of the healthcare system: Access	3.4.1 Physical hinderances affecting an individual's ability to travel to treatment centres	<p>The Gambia: During the first years of health seeking, decisions to start or continue treatment were based on the convenience of travelling. Additionally, multiple visits for a diagnosis with semen samples for analysis and possible treatment also increases the difficulty infertile women in The Gambia face in comparison to economically independent respondents who could travel abroad for more advanced biomedical diagnostic and treatment services. (Dierickx et al. 2019)</p> <p>The Netherlands: A Dutch study highlighted that although some infertile Ghanaian women reported having a partner who resided in Ghana and visited occasionally, others reported that they lacked a stable relationship (Yebei 2000). The absence of a spouse resulted in delayed or inaccessible fertility treatments as their consistent availability is expected during treatment (Yebei 2000)</p> <p>Mozambique: Although half went principally to the hospital, all visited traditional healers at least once. Physical distance was not the main factor for fewer visits to the clinic - some traveled to famous healers further away though local ones most often used (Gerrits 1997)</p>	"... I even travelled to Senegal and the price they charged me for the operation there, I couldn't afford it. I came back to The Gambia and I agree for them to remove it together with the womb" (Dierickx et al. 2019)
Structure of the healthcare system: Affordability	3.4.2 Transport costs	<p>Mozambique: Respondents reported not travelling to the provincial capital, Pemba (200km away) due to lack of money (Gerrits 1997).</p> <p>The Gambia: Economically independent respondents who could also travel abroad for more advanced biomedical diagnostic and treatment services tend to use fertility treatment more than those who were not (Diericckx et al. 2019).</p>	"... Transport is not a big difference in terms of affordability" (Dierickx et al. 2019)

Analytical Theme: Perceived Quality of Care	Descriptive Theme: Perceived Quality of Care	Summary of Findings	Illustrative Quote(s)
<p>Patient-centred care: Folk Healing: Alternative and complementary explanations and therapies</p>	<p>3.4.4 The costs of bewitching, muankoko and spiritual bondage</p>	<p>Nigeria, Mozambique and The Netherlands: It is assumed that expenses are not the main reason for fewer visits to the hospital in comparison to traditional healers as the respondents interviewed sometimes paid more for services offered by the latter than the former.</p> <p>Women are prepared to spend more money on traditional treatment than ART when illness is perceived as being caused by:</p> <ul style="list-style-type: none"> (i) Witchcraft: The untoward acts of people or witches (e.g., being given tea unknowingly made of particular medicinal plants or the victim of a secret spiritual ritual performed by, or at the request of, an adversary using belongings or body parts stolen from the subfertile woman in question); (ii) Spiritual possession: Spirits ('majini' or 'maleika') are believed to prevent sexual intercourse with their spouse or be the underlying reason men refuse to remain committed to them; (iii) Naturalistic causes such as the 'mismatch' of blood between spouses, 'muankoko' or 'norro' (gonorrhoea) which is thought to destroy their 'belly' or uterus <p>However, authors also highlight that affordability related to the level of treatment offered from traditional healers affects their likelihood of proceeding with it.</p> <p>Most sub fertile women were treated with contraceptives, herbal teas, balms or baths that were either self administered at home or by herbalists who they perceived were competent enough to also diagnose and treat STDs.</p> <p>Those that were deemed spiritually possessed were expected to undergo a more expensive exorcism ritual consisting of dancing, drumming, drinking herbal teas/baths and offering of prayers to spirit beings. Treatment could also involve fortune tellers, indigenous healers or kanyaleng kafo (Dierickx et al. 2019; Mariano 2004; Hollos 2003; Yebel 2000; Gerrits 1997).</p>	<p>"In the case of spirit possession women undergo an exorcism ritual... Some of the possessed women said they could not be treated in this way because they could not afford the expenses" (Gerrits 1997)</p> <p>"There is Mandinka medicine called 'simanko la' meaning 'after dinner', while others called it 'nbenki' meaning 'aunty'. It has two different names but it is the same medicine. When you want to buy it, that's the name you use but the real name is tobacco powder. People say it used to cure seketoo but I am not very sure because when you apply it, you end up crawling on the ground, that medicine is not a joke... It cause dizziness, and you will not be able to talk and it makes you vomit all the time... some encounter diarrhoea" (Dierickx et al. 2019)</p> <p>"Somebody told me about one marabout at village X. When I went there he gave me holy water and some medicine but he also told me: 'be very careful because there is one person in your compound who didn't want you to marry your husband' (Rural woman, Dierickx et al. 2019)</p> <p>"Before Jammeh (a marabout) left, nobody dared to talk about infertility. Nobody would say "you need to go to the hospital" because he had his own program. . . Some women claimed to be cured by him, however, they did not have many other options than to say this. You could not encourage people to go for a scan in the health centre" (Urban woman, Dierickx et al. 2019)</p>

Analytical Theme: Perceived Quality of Care	Descriptive Theme: Perceived Quality of Care	Summary of Findings	Illustrative Quote(s)
Structure of the healthcare system: Affordability	3.4.2 Prescription Costs	<p>The Gambia: Laboratory tests/ medicines purchased outside of the health sector deemed fertility treatment even under the public health sector too high for respondents to undertake (Dierickx et al. 2019)</p>	"if you can pay for the health centre and the medication, you can also pay for the transport. Money is the only difficulty" (Dierickx et al. 2019)
Structure of the healthcare system: Affordability	3.4.2 Treatment Costs	<p>The Gambia, Botswana and The Netherlands: Due to existing wealth inequalities, the costs associated with the private health sector put fertility treatment out of reach for most (who had no insurance and were not financially independent)</p> <p>Even with limited resources, women sought funds required to access the public health sector at least once or waited extensive periods of time between visits as they lacked immediate funds for direct payments required</p> <p>The financial burden led some husbands to discourage treatment (Dierickx et al. 2019; Mogobe 2005; Yebei 2000)</p> <p>The social and economic problems of 'undocumented' Ghanaian women in The Netherlands were numerous and hindered their access to the national health insurance (Yebei 2000). Although the interviewees were allowed to utilise ART, having low paying 'illegal' jobs limited their ability to afford private health insurance or the direct payments required. For this reason, respondents opted to undertake alternative fertility treatments. Additionally, like the studies conducted in Africa and the UK (Dierickx et al. 2019; Dierickx et al. 2018; Bailey et al. 2017; Fledderjohan 2012; Weinger 2009; Mogobe 2004; Mariano 2004; Roberts & Franklin 2004; Hollis 2003; Gerrits 1997), authors report that although public health insurance in the Netherlands also covers reproductive technology use, treatment costs are generally high. Limits to the number of treatment trials reimbursed by public health insurance bodies may subsequently affect the number of attempts that women may have preferred to undertake (Yebei 2000).</p> <p>UK: Investing their funds into redundant treatments results in reconsideration of the emotional and practical costs and questioned their access to sufficient resources for treatment (Bailey et al. 2017; Roberts & Franklin 2004)</p>	"You're then saying to yourself 'Well, the chances of me getting pregnant naturally are sort of slim to none', you know, 'so if I don't do it I give up. If I do do it, I'm borrowing money I don't have'... I'm not sure I want to do that... for me at least the process is so physically demanding, so emotionally demanding. I wouldn't want to do it again" (Bailey et al. 2017)

Analytical Theme: Perceived Quality of Care	Descriptive Theme: Perceived Quality of Care	Summary of Findings	Illustrative Quote(s)
Structure of the healthcare system: Availability	3.4.3 Limited availability of Examinations and Treatment	<p>Mozambique: The means to diagnose and treat the causes of infertility was limited. For example, (i) required medicine could only be purchased 200km away (ii) the only respondent that was able to be examined and treated in the hospital (in the capital, 200 km away) was married to an employee of the national health service (Gerrits 1997)</p> <p>The Gambia: Similarly, as most of the gynaecologists in The Gambia and Mozambique who work in either the public and private sector are located in the urbanised area, Banjul, ART was inaccessible to women in rural communities (Mariano 2004; Dierickx et al. 2019).</p> <p>The Netherlands: Likewise, although all respondents in the Dutch study were using at least one biomedical treatment, issues with availability were heavily attributed to Dutch national health policy which prohibits fertility treatment to women beyond forty years old (Yebei 2000). Ghanaian women elaborated they felt unwilling to cease treatment at forty years old due to a strong cultural belief that irrespective of their age, ovulation was a sign of fertility (Yebei 2000). The author suggests this contributed to their grievance around the age restriction argument, which they found unconvincing as well as their specialist's lack of consideration of their cultural background. Adequate availability of procedures offered by modern health care facilities was also questioned. For example, some women reported that medication and dietary advice were the only options available when suffering from fibroids and repeated miscarriages respectively.</p> <p>As Dutch national health policy prohibits fertility treatment to women older than forty years old, women opted for treatment in neighbouring countries where no such policy restrictions exist (Yebei 2000).</p>	<p>"They told me that the fibroid is very big and the instrument to be used for the operation so that it will not affect my womb is not available in this country, unless I travel aboard... I couldn't afford it. I came back to The Gambia... to remove it together with the womb" (Dierickx et al. 2019)</p>

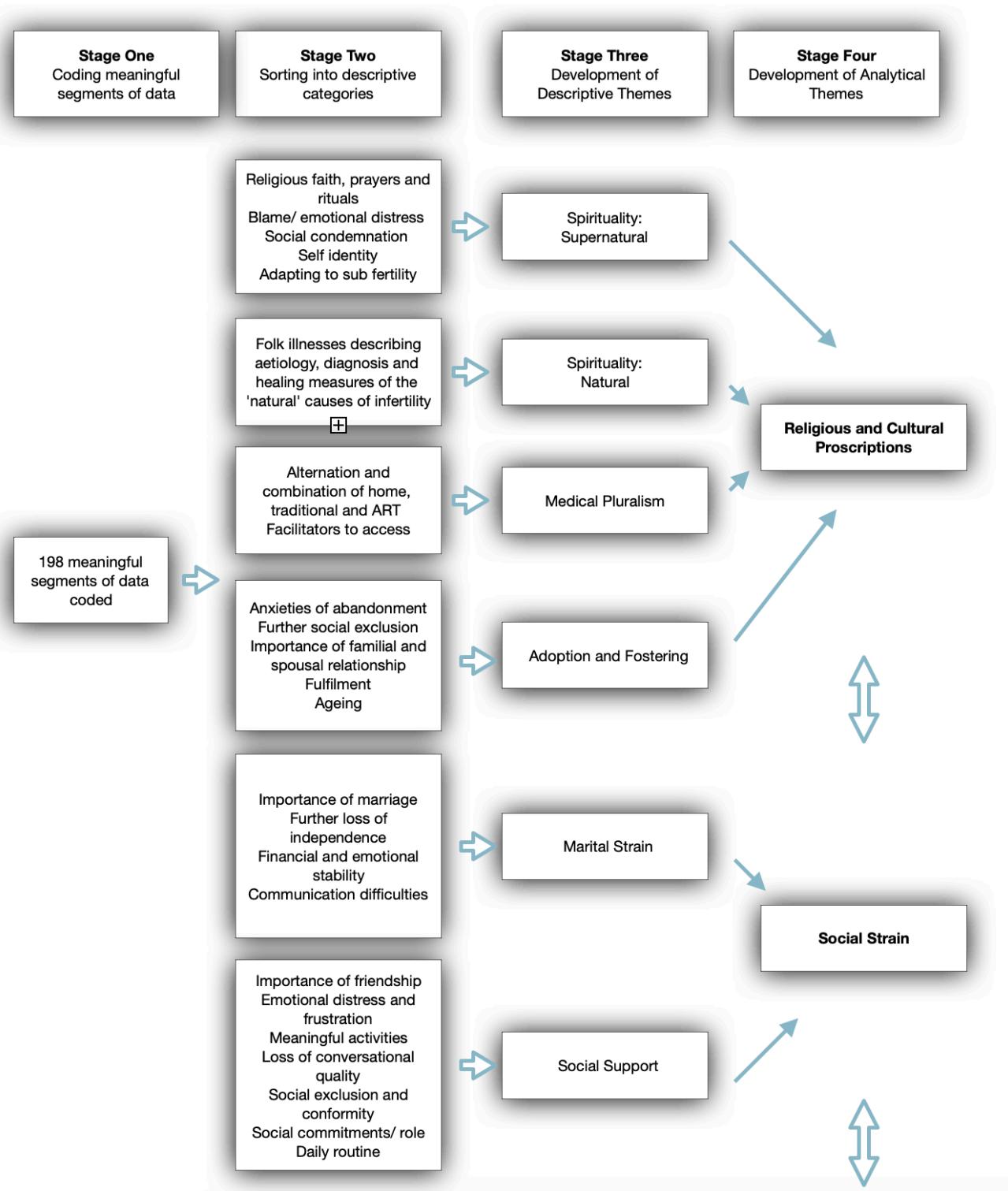
Analytical Theme: Perceived Quality of Care	Descriptive Theme: Perceived Quality of Care	Summary of Findings	Illustrative Quote(s)
Structure of the healthcare system: Availability	3.4.3 Comprehensiveness of Care	<p>Mozambique: Although respondents could describe the examinations, as they reported not receiving or understanding the results, authors question the comprehensiveness of care (Gerrits 1997).</p> <p>The Netherlands: Women were triggered by i) how unconvincing the argument for age restricted fertility treatment was and ii) inconsideration of their level of education or cultural background - they preferred to go to more 'understanding' doctors in Belgium and Germany (Yebei 2000).</p> <p>UK: The specificity of the current resilience model was questioned for inadequately addressing that following treatment failure when women are suffering high levels of distress, they may appraise their ability and intent to reattempt treatment (costs to emotional health, financial security and wider life goals). Additionally, after experiencing a failed ART attempt and being more aware that care professionals could not ensure success of all attempts, they sought answers they perceived their specialists were unable to provide. They expressed this made them feel empowered and helped relieve their despair (Bailey et al. 2017).</p> <p>Others felt elaboration of the possible causes of treatment failure increased their sense of trust and respect for staff as well as in clinical and scientific authority (Roberts & Franklin 2004). Authors also suggested it allowed younger couples to expand their thinking into other options if Preimplantation Genetic Diagnosis (PGD) is unsuccessful. However, the despondency older British couples felt regarding potentially undertaking alternative treatment options shared similarities with the respondents in the West and Southern African studies (Mogobe 2005; Weinger 2009; Roberts & Franklin 2004; Hollos 2003; Yebei 2000). British women were plagued by anxieties related to the 'spectre' of 'wasted' years and resources lost to repeated attempts, particularly those whose social lives and careers were disrupted whilst undertaking PGD (Roberts & Franklin 2004). It is thus unclear whether clinical practice is adequately sensitive to their burdens and comprehensiveness enough to adequately interrogate whether individuals have sufficient resources to prevent further depletion of their physical and mental wellbeing.</p>	<p>"... if you compare the way I go in and the terms I use, it's like a professional talking... You don't trust anyone any more you think you know the best" (Bailey et al. 2017)</p> <p>"... they talked through everything... they were brilliant. They were very clear. They explained everything really clearly and really like, not patronisingly but very simply, so you didn't feel silly about asking questions about things. They showed us lots of pictures as well so it was like very easy to understand exactly what was happening. Um, they talked to us about how we felt about it, and sort of, I think, made sure that we understood exactly what was going on and... also made it very clear that it wasn't you know, that the, the actual chances of it working... are—it's not a certainty. You don't say "Oh I'm having PGD so therefore I'm going to walk away with a baby" (Roberts & Franklin 2004)</p> <p>"... I can't give my all to the job... I've got other issues at home!... What happens if things don't go to plan, and we are childless? I'm not going to have a career to push myself into... I've kind of put that on hold!" (Roberts & Franklin 2004)</p>

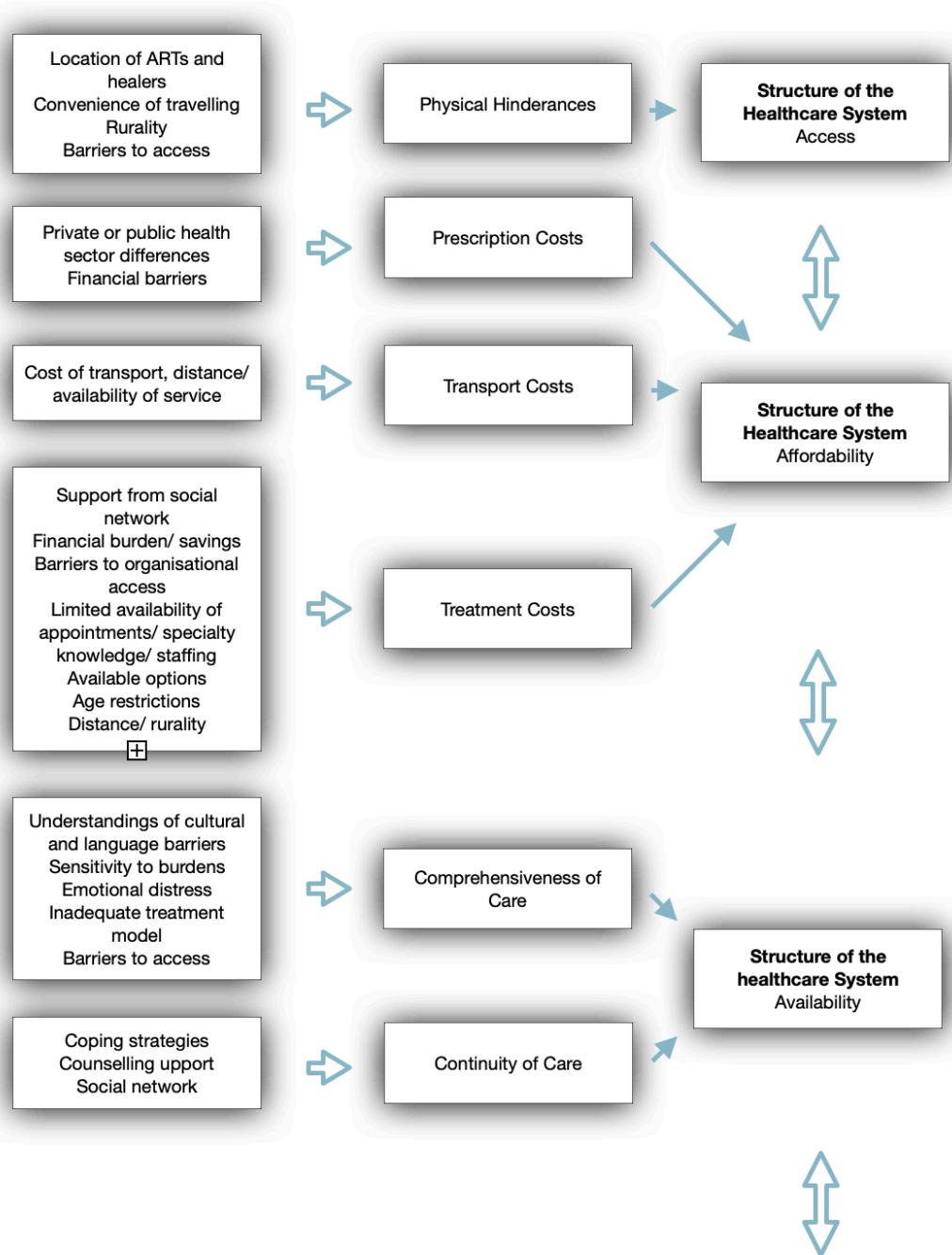
Analytical Theme: Perceived Quality of Care	Descriptive Theme: Perceived Quality of Care	Summary of Findings	Illustrative Quote(s)
Structure of the healthcare system: Availability	3.4.3 Continuity of Care	<p>UK: Although women spent their time away from cycles accessing professional support or activating support networks, it was uncertain whether respondents sought this due to inadequate or non-existent provision from their ART clinic (Bailey 2017)</p> <p>Botswana: Believing they had exhausted all interventions, women emotionally distanced themselves from the struggle of 'denying' their needs by engaging in more community service, busying themselves with their career and discontinuing treatment (Mogobe 2005)</p> <p>These experiences provide insight into the 'invisible epidemic' in which patients from poorer communities and suffering with multiple health problems (co-morbidities) are frequently subjected to fragmented care that often cause more harm than good (Mangin & Garfinkel 2019).</p> <p>Patients with complex co-morbidities may also present in similar ways to many ART clinics across the world - the amalgamation of precarity and multiple social traumas may cause or exacerbate existing psychological and physical illnesses. In this way, even women residing in high income countries with access to ART may be vulnerable and at high risk of being adversely affected by poorly integrated care and support services if they live in socially deprived communities and suffer from multiple health conditions (Ecks 2020).</p> <p>For this reason, allow more time/ space for women to talk about their lives and needs during consultations may allow deeper exploration of underlying complex problems. This may subsequently foster better integrated care that is more patient-centred, co-ordinated as well as individually tailored to their needs and empower them to shape the services they receive and challenge what falls short of what 'good' should look like (Department of Health & Social Care 2013).</p>	<p>"I've always spoke to somebody around me that I know will just listen to me [...] they've given me that morale boost and put me back into my mental happy positive state" (Bailey et al. 2017)</p>
Patient-centred care: Beyond Technical Execution of Care: Dignity, Trust, Respect and Humanised Care	3.4.5 'Have they given up on me?': Developing alternative strategies to facilitate healing	<p>The Netherlands: Women reported that they felt medical doctors hesitated to prescribe medicines which they believed led to quicker recovery (Yebei 2000).</p>	<p>"Belgium doctors are very encouraging; it does not matter how old you are... (I) have to buy the medicine prescribed... Here [Netherlands] insurance pays for me and maybe that is why they [health system] are less helpful" (Yebei 2000)</p>

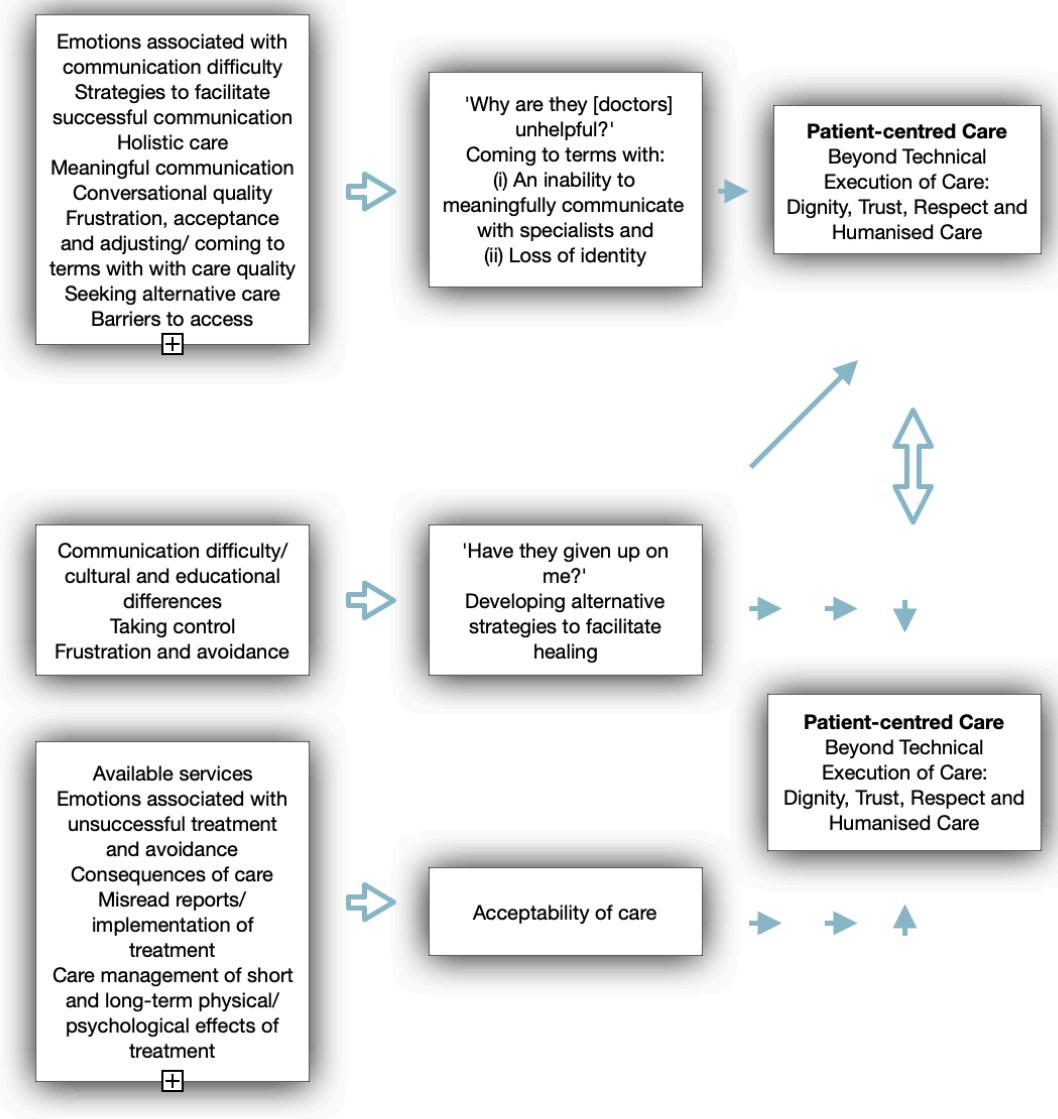
Analytical Theme: Perceived Quality of Care	Descriptive Theme: Perceived Quality of Care	Summary of Findings	Illustrative Quote(s)
Patient-centred care: Beyond Technical Execution of Care: Dignity, Trust, Respect and Humanised Care	3.4.5 'Why are they [doctors] unhelpful?': Coming to terms with (i) An inability to meaningfully communicate with specialists and (ii) Loss of identity	<p>The Netherlands and Mozambique: Inter-cultural misunderstanding led to the misinterpretation of clinical decisions, poor communication and rapport.</p> <p>In order to investigate the adequacy of the processes of patient-centred care, authors explored the interpersonal interactions between staff and users. For example, respondents felt their treatment was ineffective as it was characterised mostly by 'endless tests' rather than medicines (Yebei 2000). The author suggests believing that taking medicine is reflective of good treatment is the consequence of inter-cultural misunderstanding and possibly led to the misinterpretation of clinical decisions.</p> <p>Additionally, doctors were perceived as being indifferent and too technical in their approach. Respondents complained of insufficient feedback on their diagnosis and prognosis and recounted that they wanted to be informed of prognosis and management strategies. Research highlights the potential inadequacy of Dutch and Mozambican after care or counselling services and suggests this subsequently drives their need to pursue further treatment abroad with 'more understanding' Ghanaian doctors or spiritual healers and herbalists who more easily prescribe hormonal medicine (Mariano 2004; Yebei 2000).</p> <p>For instance, treatments not comprehensively explained in English and group education sessions/ written information on treatments did not provide interpreters or translated materials from Dutch. Although support groups existed, they were unaware.</p> <p>Additionally, although Mozambican research illustrates prescribed treatments from healers were not always efficacious, researchers still question whether an approach that does not allow women to 'release their pain', like holism does, is effective enough (Mariano 2004).</p> <p>Some left The Netherlands to holiday in Ghana with the sole purpose of seeking treatment/ alternative strategies with spiritual healers or herbalists (Yebei 2000)</p>	<p>"... many of the respondents went to "more understanding doctors" in Ghana for further treatment. There they were more easily prescribed hormonal drugs and freshly prepared herbs" (Yebei 2000)</p>

Analytical Theme: Perceived Quality of Care	Descriptive Theme: Perceived Quality of Care	Summary of Findings	Illustrative Quote(s)
Patient-centred care: Beyond Technical Execution of Care: Dignity, Trust, Respect and Humanised Care	3.4.6 Acceptability of care	<p>Africa and The Netherlands: Limited availability of gynaecologists in rural areas of The Gambia and Mozambique influenced complaints relating to the need to receive care more promptly (Dierickx et al. 2019; Mariano 2004). The need for prior appointment before treatment, accompaniment of spouse as well as scheduling difficulties experienced whilst arranging appointments may be indicative of institutional barriers. It is possible that the reduced availability of doctors contributed to longer waiting times and dissatisfaction. Empirical evidence has highlighted that difficulty in accessing primary care influences the degree of responsiveness in Europe and in Africa (Sánchez-Piedra & Prado-Galbarro 2014; Mohammed et al. 2013).</p> <p>Specialists' attempts to reassure Dutch users that they were "all right" and could bear children without further intervention made them feel that specialists did not demonstrate a capacity to listen attentively or consider their cultural and religious needs (Yebei 2000). As attentive listening facilitates good communication and understanding of the individual physical, psychological and social dimensions of the user, the lack of attention from specialists appeared to increase the distance between them and result in negative evaluation. Communication was also perceived as being unsatisfactory because the information they deemed necessary about sub fertility and treatment to resolve their concerns was unprovided. The extent to which this information was understood may have been limited by language difference between Dutch speaking specialists and the English or Ghanaian speaking users. Studies have emphasised good specialist-user relations beyond technical aspects strengthen confidentiality, dignity and humanised care (Matiti 2002).</p> <p>The Netherlands, The Gambia and Mozambique: Communication, access and waiting times were negatively evaluated - reduced availability of specialists, lack of attentiveness around the psychosocial dimensions of the user, requirement of spouse at appointments and scheduling difficulties acted as institutional barriers which contributed to longer waiting times and dissatisfaction (Dierickx et al. 2019; Mariano 2004; Yebei 2000)</p>	<p>"They told me that the fibroid is very big and the instrument to be used for the operation so that it will not affect my womb is not available in this country, unless I travel aboard. So, I even travelled to Senegal and the price they charged me for the operation there, I couldn't afford it. I came back to The Gambia and I agree for them to remove it together with the womb" (Urban infertile woman, Dierickx et al. 2019)</p> <p>"There was a man who fooled me. Still now I won't forget. He said he is a medical nurse, he said I have an UTI... that is seketoo. In our tradition we have the believe that it can be cut. Now I know that I do not have it but at first I thought it was true and that I had it. He wanted to have money from my husband and the nurse said the solution is to cut it out and my husband asked him the price, he said D1000 [21 USD] [laughing]... my husband gave the nurse the money... when I went to his place, on the whole he did not know what is an UTI. So, he was checking me and touched my clitoris and I told him 'that's not the one'. Then I told him: 'you have taken the money just go your way'" (Dierickx et al. 2019)</p>

Figure III: The Development of Descriptive and Analytical Themes







3.4.1 Access

Gambian, Mozambican and Dutch studies reported issues with access to the healthcare system (Dierickx et al. 2019; Yebei 2000; Gerrits 1997). During the first years of health seeking, decisions to start or continue treatment were based on the convenience and cost of travelling. A Dutch study highlighted that the absence of their Ghanaian residing spouses resulted in delayed or inaccessible fertility treatments as their consistent availability is expected during treatment. Gerrits (1997) reported that although the majority of infertile women searched for medical treatment to solve their infertility issues, only half of them went principally to the hospital in Montepuez, Mozambique but all visited traditional healers at least once. Authors also highlight that some women visited as many as thirty different healers. It was noted that perceived aetiology of illness rather than physical distance may principally explain fewer visits to the hospital in comparison to general healers as journeys due to the institutions are generally shorter.

3.4.2 Affordability

Three studies conducted in The Gambia, Mozambique and Botswana (Dierickx et al. 2019; Mogobe 2005; Gerrits 1997) in Africa and three studies conducted in The Netherlands and the United Kingdom (Bailey et al. 2017;

Robert & Franklin 2004; Yebei 2000) in Europe have also highlighted issues regarding financial barriers to treatment. A Mozambican study reported that as prescribed medicines were unavailable in the hospital pharmacy, although they were referred to the provincial capital, Pemba (200km away), none went as they lacked transportation costs so resorted to buying prescribed medicines at the local market (Gerrits 1997).

Studies reported that although infertile women in Gambian and Botswanan communities spent significant amounts of their savings to get pregnant, the type of fertility treatment women pursued was dependant on their finances (Dierickx et al. 2019). Some contacted people within their social network for financial assistance (Dierickx et al. 2019; Mogobe 2005). However, it was also highlighted that the financial burden imposed led some husbands to discourage ART. Apart from the few respondents who were financially independent or had insurance, the costs associated with the private health sector in the West Coast region of The Gambia put ART under the private sector out of reach for most due to existing wealth inequalities (Dierickx et al. 2019). Despite lacking resources, the social pressure to become pregnant was so strong, that even women with limited resources sought the funds required to access the public health sector at least once. However, the fact that respondents deemed public sector fees, laboratory tests and even medicines purchased outside of the health sector too high, is indicative of inaccessibility. Respondents also reported waiting extensive periods of time between visits to the health centre due to insufficient funds for subsequent steps (Dierickx et al. 2019).

3.4.3 Availability

Gambian, Mozambican, Dutch and British studies illustrated that availability was a barrier to ART (Dierickx et al. 2019; Gerrits 1997; Yebei 2000; Bailey et al. 2017). For example, Mozambican women reported that their hospital visit was due to the community awareness raised from the findings of an epidemiological study at Montepuez hospital. Research highlighted the relationship between infertility, STDs and guaranteed availability of medicines to treat particular STDs (Gerrits 1997). However, the limited means to diagnose the causes of infertility was indicative of organisational access issues, in particular, the availability of examinations.

Likewise, the provision of adequate counselling services was also questioned in UK studies involving White British, Irish, Latvian and mixed White Asian ethnicities (Bailey et al. 2017; Roberts & Franklin 2004). The Infertility Resilience Model currently implemented to describe the process of resilience does not specifically provide a theoretical explanation of the various ways different ethnicities demonstrate their resilience in adapting to the challenges associated with repeated failed attempts (Bailey et al. 2017). The authors suggest that because clinicians in the UK may not be equipped to fully support their client's need to either continue to pursue their pregnancy goal or withdraw from ART, the provision of care may be compromised (Bailey et al. 2017). However, unlike the African respondents, when respondents stepped away from treatment to restore their strength, they had more access to professional support or support networks (Bailey et al. 2017). Like African respondents though, UK respondents also reclaimed the control they gave to professionals in the initial treatment stages and searched for answers that they felt their doctors were unable to provide outside the modern healthcare system (Bailey et al. 2017). Authors suggest this reclamation of control enabled them to let go of the despair experienced after conception failure. However, unlike African participants, they believed the effectiveness of alternative treatments was limited. Authors highlight being driven by the act of trying to do something they perceived was important emboldened them to feel less 'stuck in limbo' and able to hold on to the hope of a successful outcome and feel a sense of control in an uncertain process (Bailey et al. 2017). Authors suggest a more patient-centred approach empowering participants with a more active role in their treatment may help resolve feelings of precarity (Bailey et al. 2017). A higher degree of transparency in the decision-making processes may thus potentially result in women feeling more empowered during ART as well as better positioned to develop more appropriate coping strategies that may improve their psychological risk profile following unsuccessful PGD.

3.4.4 Folk healing: Alternative and Complementary Therapies

It is assumed that expenses are not the main reason for fewer visits to the hospital in comparison to traditional healers as the respondents interviewed sometimes paid more for services offered by the latter than the former (Refer to Table V for 3.4.4).

3.4.5 Beyond Technical Execution of Care: Dignity, Trust, Respect and Humanised Care

Inter-cultural misunderstanding led to possible misinterpretations of clinical decisions, poor rapport and for some, the discontinuation of care (Yebei 2000) (Refer to Table V for 3.4.5).

3.4.6 Acceptability of Care

In regards to service responsiveness, healthcare in hospitals was not evaluated as favourably as indigenous traditional healers and herbalists by subfertile women in the African and Dutch studies (Dierickx et al. 2019; Dierickx et al. 2018; Mogobe 2005; Mariano 2004; Yebei 2000; Gerrits 1997). Access and waiting times were negatively evaluated particularly because it was not possible to meet spontaneous demand (Refer to Table V for 3.4.7). It is unclear whether women felt able to report complaints about their experience of accessing care. It is possible they may have feared a reprisal that may have prevented them from further treatment or may not have been aware of patient complaint processes. Dutch and Mozambican respondents complained that the experience of accessing ART affected their physical and mental health. For example, as the unpleasantness of the side effects and the emotional cost of having their expectations raised with every new treatment attempt without mention of support was stressed, it is possible that unavailable counselling services or inadequate care negatively affected their health (Gerrits 1997; Yebei 2000). However, the number of Mozambican women who were unable to be treated by herbal healers but went on to subsequently be treated successfully in hospital raises wider concerns of the exposure of women to potentially predatory and exploitative services offering expensive or redundant solutions (Gerrits 1997).

3.5 Findings of Included Studies: Perceived barriers of access to fertility treatment

The following section will explore the findings of included studies and will be organised to describe perceived barriers to accessing ART (Table V).

Table V: Contents of the Findings of Included Studies

Perceived Barriers to Accessing Fertility Treatment Themes	
Religious and Cultural Proscriptions	3.5.1 Spirituality: Supernatural
	3.5.2 Spirituality: Natural
	3.5.3 Medical Pluralism: Home, traditional/ indigenous and biomedical treatment
	3.5.4 Adoption and Fostering
Social Strain	3.5.5 Marital Strain
	3.5.6 Social Support

3.5.1 Spirituality

When attempting to understand the potential barriers to fertility treatment, it is important to appreciate that a traditional religion that centres on witches, spirits, sorcerers, spirits of ancestors and traditional healers is an important aspect of how women experience and cope with their subfertility (Table VI).

Table VI: Summary of Descriptive Themes: Perceived Barriers to Access

Analytical Theme: Perceived Barriers to Access	Descriptive Theme: Perceived Barriers to Access	Summary of Findings	Illustrative Quote(s)
Religious and Cultural Proscription	3.5.1 Spirituality: Supernatural	<p>Africans: Infertility was attributed to in-laws, immoral behaviour, witchcraft or ancestral curses. They sometimes turned to traditional healers and religion for strength alongside medical treatment (Dierickx et al. 2019; Fledderjohan 2012; Weinger 2009; Yebei 2000)</p> <p>Cameroonian women were hesitant to accept major medical interventions fearing it was "working against God's will" (Weinger 2009). Although Botswanan women were unsure how, convinced they offended God, some questioned, "Ga ke itse gore Modim eng" (what they had done) (Mogobe 2005). Women reason faith grounded them in God's power and believed church attendance strengthened their faith.</p> <p>Ghanaian women perceived infertility as a spiritual, rather than physical problem that ultimately requires redress of the social and psychological aspects they believe underlie it (Yebei 2000). Unlike UK respondents, the perceived importance of spirituality was not affected by awareness of ART even when resources were emotionally and practically exhausted (Yebei 2000; Bailey et al. 2017).</p> <p>Priests and pastors helped Ghanaian women cope and in some churches, individualised prayer programmes tailored uniquely to them were developed.</p> <p>UK: In contrast, religion was not used as a coping mechanism. When practical and emotional resources were exhausted, they temporarily discontinued treatment to reconnect with their 'normal' lives that did not centre on fertility (Bailey et al. 2017)</p>	<p>"Most of this is attributed to witchcraft... If you are 36, 38, and you haven't had a child, people will say it is because of something from a former life, or it is your grandmother, witchcraft, or that your womb has been taken to the North or is being used for ritual purposes" (Fledderjohan 2012)</p> <p>"... rather than spending hours trying to research my cure for myself... through sort of looking at stuff online, reading papers, whatever, I'm practising my singing and practising my yoga... I'm enjoying those things" (Bailey et al. 2017)</p>
Religious and Cultural Proscription	3.5.2 Spirituality: Natural	<p>The Gambia: Attention is given to folk illnesses (including fibroids) that are detectable through biomedical approaches, prior abortions, overdoses of family planning tablets or injections.</p> <p>Other respondents perceived infertility or miscarriage may be the result of the stress arising from the hard work involved tending to the compound, farms and gardens; a tight vagina; a weak womb that results in sperm runoff after intercourse or the presence of hot water inside the stomach (Dierickx et al. 2019).</p>	<p>"I heard from people that my brother's wife used to take the family planning tablets before she got married. Now... she could not become pregnant and people said that she overdosed herself with the tablets" (Dierickx et al. 2019)</p>

Analytical Theme: Perceived Barriers to Access	Descriptive Theme: Perceived Barriers to Access	Summary of Findings	Illustrative Quote(s)
Religious and Cultural Proscription	3.5.3 Solutions: Medical Pluralism - Home, traditional/ indigenous and biomedical treatment	<p>As indicated by frequent alternation and combinations of pursued treatment, Ghanaian, Botswana and Gambian women showed no preference of modern health care over more traditional methods (Mogobe 2005; Mariano 2004; Yebei 2000).</p> <p>Although all women visited private and public health centres when women perceived the cause to be due to natural factors, particularly young and highly educated women expressed a preference for private facilities, though financial barriers limited their access. Preference for private health centres was due to perceived beliefs that diagnosis tools, better equipment, professionalism and motivation levels of staff were better.</p> <p>Ghanaian respondents preferred Ghanaian herbalists in Amsterdam who dispensed herbs for infertility to doctors as they promised an immediate cure, spoke their language and patiently tackled their problem holistically in order to heal their body and 'broken' social networks (Yebei 2000). Herbalists were also favoured because of their affordable fees, more accessible locations, expeditious appointments that lasted as long as the women required and flexible consultation schedules. Additionally, as payments could be made in instalments, they were more accessible to those on a low income. However, those that did not use herbalists were dubious about them for religious reasons and as Christians, avoided them as they were concerned herbalists operated under evil influences.</p>	

Analytical Theme: Perceived Barriers to Access	Descriptive Theme: Perceived Barriers to Access	Summary of Findings	Illustrative Quote(s)
Religious and Cultural Proscription	3.5.4 Solutions: Adoption and Fostering	<p>The Netherlands, Nigeria and Botswana:</p> <p>Interestingly, after all attempts at conceiving a biological child failed, a rare strategy considered by the women who underwent ART was adoption. Although all Botswanan women were aware of the traditional form of adoption, few were aware this was an option and of the few who understood its legal process, resistance from spouses and/or relatives was faced (Mogobe 2005).</p> <p>Women had misgivings about customary adoption due to lack of spousal and familial support and fears of potential rejection if their child returned to their biological parent/s (Yebei 2000). Their concerns regarding customary adoption was due to potential rejection if their child decided to return to their biological parent(s), anxieties of possible parental intervention or a custody challenge if there were welfare concerns and apprehension of the child 'inheriting' the bad character traits of their biological parents (Mogobe 2005; Hollos 2003; Yebei 2000).</p> <p>Similarly, although Cameroon women reported their non biological children are like their own and eased the pain of their childlessness, they questioned the legitimacy of the bond (Weinger 2009; Yebei 2000). Likewise, although Nigerian respondents fostered children from relatives, agricultural work was often a motivating factor and they expressed that it did not fill their emotional void (Hollos 2003). In contrast, women from Mozambique expressed great interest in adoption (Gerrits 1997). However, although more than half of the respondents cared for mainly their relatives' children, Botswanan, Ghanaian, Nigerian and Cameroonian women reported problems. For example, biological parents at times accused them of mistreatment or exploitation whereas others complained they felt at times that children they cared for disobeyed them because they are "not the real mother".</p> <p>UK: Unlike studies conducted with women of African descent, there is more emphasis on the 'internal force' driving the need of British women to have their own biological child (Bailey et al. 2017; Roberts & Franklin 2004).</p>	<p>"Sometimes I think that if this was my own child he wouldn't react that way to me. I think if this was my own child I would treat him differently" (Weinger 2009)</p> <p>"Some people are a lot more accepting and think 'OK what are our other options?'... 'We can adopt'. I just kind of really desperately want to become pregnant" (Bailey et al. 2017)</p>

Analytical Theme: Perceived Barriers to Access	Descriptive Theme: Perceived Barriers to Access	Summary of Findings	Illustrative Quote(s)
Strained Social Interactions	3.5.5 Marital Strain	<p>Africans: Few marriages were able to manage the long-term impact of infertility. Some women reported physical, emotional and financial abuse and feared divorce (Dierickx et al. 2018; Fledderjohan 2012). Although Gambian respondents shared gossip of others they knew in extramarital relationships, in practice, the consequences were less severe for men in Gambian, Ghanaian and Mozambique culture as it is considered to be in their 'nature' (Dierickx et al. 2018; Fledderjohan 2012). Women confessed if their husband was infertile, becoming pregnant even with another man was better than risk divorce.</p> <p>Muslim respondents feared their husbands would engage in polygyny. Although men were supposed to engage in polygyny only if they had the financial means, in practice, economically, infertility impacted the daily lives of women regardless of their financial position. For example, as sons receive double the share of the inheritance than wives under Sharia law, co-wives or in-laws can expel childless widows with limited resources after their husband's death. Nigerian women also expressed marginalisation from relatives as a result of polygyny (Hollos 2003).</p> <p>The experience drove women to either initiate divorce, have extramarital relationships to become pregnant or 'marry' another woman. In this latter case, paying another woman's bride price in order to lay a claim to future children the new wife had with her husband was believed to be a stronger alternative to simple fostering. This strategy also relates to traditional Tswana custom where a husband has a right to ask his spouse/ her family to provide him with another woman to bear children (Mogobe 2005).</p> <p>Interestingly, apart from Nigerian respondents who most frequently initiated divorce, African women rarely left despite their discontent, as they believed marriage was an important social and cultural institution (Hollos 2003; Mogobe 2005; Dierickx et al. 2018). African women highlighted the difficulty women faced discussing marital issues, sexuality and infertility amongst another or specialists and reported that even conversations about infertility related pains were vague (Dierickx et al. 2019).</p>	<p>"Having children is also important for the economic security of women. When a woman remains childless, the husband will refuse to give his wife fish money or to provide clothes. She is chased away directly, but commonly indirectly by not providing financial support. These women will often return to the compound of their parents" (Dierickx et al 2018)</p>

Analytical Theme: Perceived Barriers to Access	Descriptive Theme: Perceived Barriers to Access	Summary of Findings	Illustrative Quote(s)
Strained Social Interactions	S3.5.6 Social Support	<p>Africans: Being denied appropriate status in society made them feel their personhood was disintegrating. Some exhibited symptoms of depression ranging from crying to insomnia to suicidal ideation. As a result, they were careful to conform and moved between reality and denial as a coping mechanism to the emotional devastation of social exclusion (Mogobe 2005).</p> <p>The Gambia: Women reported the kanyaleng kafoo provided them with social, emotional and even financial support. Tensions with in-laws, particularly mothers-in-laws escalated whilst living within the same compound, as customs dictate, as they were subjected to harassment. The bride price also exacerbated issues with in-laws. Although the price between ethnic groups and family differed, it often consisted of a large amount of goods, cash or animals. As this exchange illustrated a transfer of the reproductive capacities of a woman to her husband's family, in-laws argued they had not received a 'good' wife who could bear children in return.</p> <p>Stable employment also allowed women to escape the stigma faced in rural communities (Dierickx et al. 2018). Women residing in urban communities even received financial assistance from employers and a forum (a therapy management group) to discuss their fears and concerns in open to their husbands, relatives, friends (Dierickx et al. 2019).</p> <p>Ghana: Women were excluded from community decisions and activities (e.g., child rearing conversations/ discouraged from interacting with children) (Fledderjohan 2012).</p> <p>Botswana: Women emotionally distanced themselves from the pain of unsuccessful treatment, stigma and 'denying' their needs by focusing on community service, their career and the idea of permanently discontinuing treatment (Mogobe 2005).</p> <p>UK: Women excluded themselves from others even if it was at the expense of having a wide social network. They felt a sense of responsibility to others, were afraid of being a burden and were wary of societal attitudes (Bailey et al. 2017; Roberts & Franklin 2004).</p>	<p>"There is a lot of social stigma... my first child after five years of marriage and that one passed away... It took me another four years to become pregnant. Sometimes... I will be hearing... throwing words at me..." (Dierickx et al. 2018)</p> <p>"... I haven't wanted to be in the same environment as my sister-in-law, especially when she was late in her pregnancy and just recently when the baby's been born, because I've found it quite difficult to be around her" (Bailey et al. 2017)</p> <p>"every decision.. affects everyone else as well, all our friends, our families. Every decision we make is indirectly going to affect somebody else, and I think that's where a lot of people don't seem to get..." (Roberts & Franklin 2004)</p>

The emotional impact of infertility was felt by Ghanaian, Botswanan and Gambian who tearfully reported feeling sad and lonely and exhibited symptoms of depression ranging from crying and insomnia to neglected personal hygiene and suicidal ideation (Dierickx et al. 2018; Fledderjohan 2012; Mogobe 2005; Yebei 2000). This lasted sometimes up to twenty years as they looked for treatments and imagined a painful childless future, without this source of fun, companionship and potential care at older age (Dierickx et al. 2018). Inability to talk about the stress and fear they experience because infertility is considered a taboo topic may have exacerbated their distress (Dierickx et al. 2018). A deeper hidden meaning for their suffering is sought through prayer and spirituality in an attempt to overcome their ordeal (Weinger 2009; Mogobe 2005). Access to information relating to the prevention and aetiological understanding of infertility was limited and attributed it to (Dierickx et al. 2019):

3.5.1.1 Supernatural ('kuntufengo'): African Traditionalism

The origin of women's infertility is attributed to invisible spirits, colloquially called 'jinnoo' believed to target beautiful and talented Gambian women from birth (Dierickx et al. 2019). Interviewees also complained community members accused them of being witches as they believed infertile women paid the highest price to participate in a credit and debt system of the 'witches club' to own other people's existing or future children (Dierickx et al. 2019). Some of the women perceived themselves as victims of 'black magic' from a marabout, a male healer affiliated with Islam, who are mainly associated with protection and treatment of afflictions caused by 'buwaa' and 'jinnii' (Dierickx et al. 2019). Co-wives and family members particularly mothers-in-laws were commonly accused of requesting affliction from marabouts. Mozambican and Dutch studies illustrated that infertility was believed to be caused by people, witches or sexual contact with the spirits, 'majini' or 'maleika', which prevented intercourse between spouses (Yebei 2000; Gerrits 1997). Botswanan and Ghanaian women also felt infertility was the consequence of chastisement by God, "petso ya Modimo", immoral behaviour, becoming pregnant at an early age, prior abortion, marrying a man without receiving 'lobulo'⁶ or consulting the ancestors as well as not following ancestral traditions (Fledderjohan 2012; Mogobe 2005; Mariano 2004). Authors also illustrated the importance of sacred places to infertile Gambian women as points of prayer or rituals, performed by herbalists, marabouts, kanyaleng kafoolu⁷ and kankurangs⁸. Religious faith and prayer was used as a means of coping with loss, disappointment, social condemnation and suicidal thoughts (Weinger 2009).

3.5.2 Spirituality: Natural

Researchers describe folk illnesses as syndromes within a culture which provides an alternative aetiology, diagnosis or healing measure which include natural causes, such as fibroids, 'seketoos⁹' and 'buluntoos¹⁰' (Dierickx et al. 2019). Mozambican and Gambian respondents also identified a 'mismatch' between the blood of spouses, 'norro'¹¹ as the most pertinent and commented that the suffering from 'xilume' (menstrual cramps), vaginal itching and discharge women experienced were commonplace within polygamous marriages and the result of STDs (Mariano 2004; Gerrits 1997).

3.5.5 Solutions: Marital Strain

⁶ Bride price

⁷ Organisations solely consisting of women who have experienced child loss or fertility issues and perform rituals to beg God to heal them of their subfertility or child mortality issues through the exorcism of evil spiritual forces (Dierickx et al. 2019)

⁸ Family of masquerades wearing a costume from tree bark fibres and leaves commonly associated with the spiritual world and perceived to have supernatural powers (Dierickx et al. 2019)

⁹ Respondents reported that the symptoms of seketoos includes itching in the general area which could lead to bleeding; white discharge; small and bumpy structures within the vagina (Dierickx et al. 2019)

¹⁰ Although little information about buluntoos is available, it is reported that abdominal back pain which is described as a stone in the womb, typically characterise this condition (Dierickx et al. 2019)

¹¹ Local term: Gonorrhoea (Gerrits 1997)

Gambian and Botswanan women perceived that the cause of infertility was gendered and because they felt stigmatised by their community and spouses, they found it difficult to encourage their spouses to be tested, diagnosed and treated and struggled to share burdens with them due to fears of potential discord (Dierickx et al. 2019; Dierickx et al. 2018; Mogobe 2005). Authors suggest this may explain the reason women were more likely to seek ART than men. Women also complained that although gender roles prescribed that men should provide 'fish money'¹², they did not receive it and as a housewife, lacking economic strength left them unable to negotiate in their relationship and vulnerable to the anxieties of abandonment (Dierickx et al. 2018). Few marriages were able to manage the long-term impact of infertility. Some reported physical, emotional and financial abuse from community, partners and in-laws. A woman's financial positioning and a man's age, education, history of childlessness with other partners and ability to opt out of an arranged marriage affected the likelihood of these outcomes (Dierickx et al. 2019; Dierickx et al. 2018; Fledderjohan 2012). In practice, the consequences of extra-marital relationships were less severe for men. If husbands were the cause of infertility, it was better to secretly become pregnant with another man than risk divorce.

3.5.6 Social support

Gambian women in weaker financial positions were more likely to be restricted to traditional roles and be presented with less opportunity to escape the tension and hurtful comments from their in-laws and community members (Dierickx et al. 2018). They were called 'a witch' and accused of 'eating their own children'. Being associated with witchcraft and immorality made respondents feel alienated.

Ghanaian and Gambian women also expressed that they felt their friendships with fertile women were qualitatively different compared to those fertile women had with one another and complained of being excluded from ceremonies such as nthaara¹³ (Fledderjohann 2012; Gerrits 1997). Unlike African respondents, UK respondents excluded themselves from their community not because they were threatened with the prospect of abuse but because they were afraid of being a burden (Bailey et al. 2017; Weinger 2009; Roberts & Franklin 2004; Mogobe 2005). Their perception of societal attitudes and mass media descriptions of PGD as a narcissistic 'designer baby' technique contributed to their self consciousness and compelled them to prove to 'everyone' that undertaking PGD was an expression of parental obligation rather than self-interest (Roberts & Franklin 2004). Although engaging in community service, their career and temporarily discontinuing treatment helped women escape the psychological pain of 'denying' their needs, the longevity and effectiveness of this coping strategy is unclear.

¹² Money for the daily livelihood of the wife

¹³ A ceremonial procedure for pregnant Macua girls that instructs their behaviour during pregnancy and labour (Gerrits 1997)

4.0 DISCUSSION

4.1 Summary of Key Findings

This review of the literature conducted systematically identified eleven qualitative studies exploring the experiences and barriers different ethnicities of subfertile women face when accessing ART in two low, three lower-middle and two high income countries across Africa and Europe (Appendix N Table 13.0).

The findings related to perceived quality of care were categorised as access, affordability and availability under the overarching themes, structure of the healthcare system and patient centred care as well as health status and user evaluation under the overarching themes consequences of care. The findings related to perceived barriers to care included religious and cultural proscriptions as well as social strain (Tables IV and VI). The characteristics and contextual factors of subfertile women in Africa and Europe associated with poor experience and barriers to care include age (>45 - highest European age restriction for IVF); educational status (non university educated), area of residence (rural area); employment (low income or unsalaried); marital status (strained, polygamous, residing in different countries, arranged); lack of social and counselling support. However, disparities in the magnitude of the effect these characteristics had on the barriers to access and the experience of ART differed between ethnic groups. The users who participated in this study came from small, poor and remote municipalities. Many of these municipalities have been without proper health services for a long time, due mainly to a lack of qualified health personnel, especially doctors. That situation has resulted from the unequal geographical distribution of health professionals, who are concentrated in urban centres, and from encouragement for the trend towards specialised medical training, centred on the hospital and sophisticated technologies out of tune with the population's health needs and with the needs of the health system. Religious and cultural proscriptions associated with spirituality, adoption and fostering was a factor associated with barrier to access particularly in Nigerian, Botswanan, Mozambican, Ghanaian, Gambian and British women. Strained social interactions within their marriage, in-laws or relatives and community was also a factor associated with barrier to access heavily in Botswanan, British, Gambian and Ghanaian women.

Synthesising information from the qualitative literature has provided considerable insight into the longer-term needs of subfertile women of different ethnicities accessing ART. The most striking findings of the synthesis reveals the ongoing difficulties women can face in coming to terms with being subfertile, accessing ART and how they adapt to life after ART:

- Ghanaian, Mozambican and Gambian (particularly Muslim) women in polygamous or arranged marriages who have expressed depressive symptoms, have little social support and limited alternative options to ART;
- Single women or those with spouses living abroad on low incomes in rural and isolated Gambian and Nigerian communities with endemic poverty and lower rates of education than classed or non indigenous counterparts;
- Undocumented or recently immigrating non Dutch speaking persons in The Netherlands over forty years old;
- Women undertaking newer forms of ART such as PGD.

Insights into their complex belief systems show that the social network and positionality of subfertile women impact health seeking behaviour and their subsequent experience of and access to ART as affordability and availability of diagnosis and treatment dictates their pragmatism whilst searching for ART. Most African women, particularly Gambian, Mozambican and Nigerians, who attributed their subfertility to supernatural causes or folk illnesses (buluntoo and norro) and fibroids had limited knowledge about aetiology or treatment. The alternation and combination of therapies from indigenous healers and ART indicated there was no preferred treatment. Their

sometimes lengthy and intricate itineraries were guided by perceived improvements of their condition and suggests they were actively seeking to understand the underlying causes and healing process.

By collating the findings reported in individual studies, significant need for longer-term support was identified. Many of the respondents who conveyed needs in relation to longer-term care were a number of years post diagnosis, which suggests that needs may persist over a significant period of time in the absence of resolution.

4.2 Interpretation of Findings: Comparison to Existing Literature

Although utilisation of healthcare services may vary by ethnicity, health inequalities for minority ethnic populations illustrate strongly association with socioeconomic disadvantage (Sweeney et al. 2015). The structural, cultural and practical barriers (the constraints of socioeconomic disadvantage and low system and health literacy) which is demonstrated in previous work corroborate findings within this dissertation and are likely to impact access to ART (Sweeney et al. 2015; von Wagner et al. 2006). Furthermore, study findings here suggest the continuous efforts of some subfertile women to build themselves up for further treatment occurs even at the risk of the depletion of their savings (Dierickx et al. 2019; Bailey et al. 2017; Fledderjohan 2012; Weinger 2009; Mogobe 2005; Mariano 2004; Hebei 2000; Gerrits 1997). This is supported by earlier research suggesting the most common reasons for dropping out of ART are too many costs (Bailey et al. 2017; Verberg et al. 2008; Hammarberg et al. 2001). These findings support prior research that identified ethnicity as a significant factor of social deprivation or disadvantage (Heneghan et al. 2016; Spencer et al. 2016; Jones 2013). Researchers highlighted the considerable financial burden was placed on ethnic minority women in the UK impeded their access to a service in which 59% of ART procedures are not NHS-funded (Heneghan et al. 2016; Spencer et al. 2016; Jones 2013).

The ‘postcode lottery’ also limits a woman’s access to treatment. Additionally, the eligibility criteria for accessing NHS-funded ARTs creates barriers for certain women including those over 39 years old as well as those with children or are considered ‘obese’ (Iacobucci 2012). In contrast, privately funded infertility centres employ more relaxed criteria for fitness. However, IVF is expensive and costs upwards of £5000 (€5800; \$6200) for a single cycle (Heneghan et al. 2016). In addition to this, UK fertility treatment centres charge from £50 for a single blood screening test to as much as £8000 for egg freezing packages (Appendix O Table 14.0) (Heneghan et al. 2016). Additionally, legal coverage of IVF varies across Europe (Appendix J Table 10.0). This may disproportionately affect African women in particular, who earn comparatively less on average than non-African women (ONS 2019). In the US, where infertility treatment is privately funded, the cost of care is identified as the greatest barrier to access to infertility care (Quinn & Fujimoto 2016; Chambers et al. 2009). Black women, whose median household income is significantly lower (\$39,950) than the average individual median US household income (\$59,039), become disproportionately excluded from such treatment (US Census 2017). Privatised care is deemed to account for the significant racial disparities observed in access (Quinn & Fujimoto 2016). However authors also note that as disparities have also been observed within settings with mandates for universal or equal access to care, additional cultural and societal factors may also pose as impediments ranging from stigma of infertility to language barriers (Quinn & Fujimoto 2016). Therefore, although the NHS provides infertility treatment universally and privately funded clinics offer their treatment non discriminately, based on these findings, it is possible access may be unequal.

4.2.1 Engaging with service

The main constitutional principles of the NHS and its provision of ART is equality and equity. Equality and equity means that every woman - despite her social or cultural background - has good quality care (Malin & Gissler 2009). EU citizens or everyone with a permanent residency have been entitled to (almost) free health and social services. A Finish study highlighted that as the reproductive health of ethnic minorities is affected by ethnicity, class, gender and country of origin, they are at greater risk of discrimination in Western countries (Adamson et al. 2003; Davey Smith et al. 2000; Inhorn & Whittle 2001; Krieger et al. 1993; Mazroo 2003; Malin & Gissler 2009).

A 2004 UK survey illustrated the disparities in access by highlighting the low availability of African Caribbean sperm and egg donors (17) to those requesting donor oocytes (274) (Jones 2013; Hudson & Johnson 2004). These experiences may subsequently affect the health and ability of African women to utilise fertility services. In this way, we can imagine how socio-economic inequality may also impact other health issues that may impede their experience of the service. A US study highlights that racial differences in IVF outcomes in fertility treatment persist despite equal access to care (Quinn & Fujimoto 2016). This finding corroborates with that of this dissertation and UK empirical evidence which has illustrated that disadvantaged groups express negative expectations of future events (Sweeney et al. 2015). This may indicate they are more likely to expect unpleasant procedures and physical or psychological outcomes. For this reason, it is possible that the fear of receiving an unsuccessful outcome may be an important barrier for subfertile minority ethnic communities engaging with ART (Sweeney et al. 2015; Austin et al. 2009).

Finally, language and literacy were identified as important influences on the willingness and ability of subfertile women to engage with ART, particularly in The Netherlands (Yebei 2000). Communication difficulties are among the strongest influences on help-seeking behaviour as well as access to and experiences of care among minority ethnic communities (Sweeney et al. 2015). Although empirical evidence demonstrates the use of trusted relatives to translate may improve access for those who cannot access interpreters or perceive the services as unsympathetic or alienating, reliance on others may affect a user's availability to attend consultations (Sweeney et al. 2015; Greenhalgh et al. 2006).

4.2.2 Aftercare, the Continuity of Care and Mental Health

Findings suggest that the current resilience model implemented by ART clinics is inadequate in understanding the full impact of the barriers to access and experience of accessing ART varies between different ethnicities of women across Africa and Europe (Bailey et al 2017). Results demonstrate that the impact of subfertility goes beyond the individual into the relationships, mood and financial stability. The WHO International Classification of Functioning, Disability and Health (WHO ICF) recognises how biological, psychological and social influences affect health (WHO 2002). The WHO ICF framework is a conceptual model for defining and understanding health. A failure in any of the WHO ICF domains can lead to loss of health. The implication of the WHO framework is that a range of factors can influence health and this must be considered in treatment, research and policy. Findings from this dissertation support this model and suggest that psychosocial factors be considered to assist subfertile women accessing ART across Europe and Africa.

Although the WHO ICF provides a framework for recognising factors that may affect the longer-term needs of subfertile women accessing ART, it does not appreciate the complexity of their experiences, as illustrated in the thematic synthesis. Results reveal the difficulties subfertile women experience adjusting and adapting to their lives during and after ART. Some were able to come to terms with their subfertility, take control and rebuild their lives. Others struggled to adapt and were unable to overcome the loss of social status, roles and activities due to difficulty accessing ART and perceived sociocultural barriers. These findings are consistent with empirical evidence that establishes that access to and knowledge of mental health services is poor - fertility specialist counselling offered by clinics tends to be inadequate and not patient-centred (British Fertility Society 2020). Evidence suggests that patient-centred care can relieve the emotional burden of infertility, which is often seen in terms of poorer quality of life (QoL), higher anxiety and depression - outcomes African women are at significantly higher risk of developing (Forte et al. 2018; Aarts et al. 2012a; Aarts et al. 2011; Boivin et al. 2011; van Empel et al. 2010; Verhaak et al. 2007; Fearon et al. 2006). More specifically, this may also benefit African migrants than non-migrants, who have less social support from family and hence would more likely rely more heavily on support provided at the treatment centre (Forte et al. 2018; Falah-Hassani et al. 2015; Aarts et al. 2012a). The scarcity of fertility treatment centres in poor, rural nations is often rationalised in terms of population control, limited healthcare resources and the burden of other life threatening diseases (Inhorn & Birenbaum-Carmel 2008). It has resulted in untreated and

irreversible infertility across large portions of the non-Western world (Inhorn & Birenbaum-Carmel 2008; Sunday 2002; Leonard 2002; Mahar et al. 2000). Prevalence rates of 30-40% are reported in parts of sub-Saharan Africa (Hammarberg & Kirkman 2013; Leke et al. 1993). In a study combining data from 47 demographic and health surveys in developing countries it was estimated that 186 million ever-married women of reproductive age (15-49) suffered primary or secondary subfertility (Hammarberg & Kirkman 2013; Rutstein & Iqbal 2004). However, the silence surrounding infertility in resource-poor countries is resounding and may reflect a eugenic position that views infertile poor people as being unworthy of treatment because overcoming infertility contradicts Western interests in global population control (Inhorn & Birenbaum-Carmel 2008; Greenhalgh 1995). This explains the reason different ethnicities of subfertile women across Africa and Europe cope in different ways with their subfertility journey and the associated disruption to their lives. It is important to consider whether services can be shaped so that various ethnicities of subfertile women with burdens or needs least met are better supported to manage, rather than being adapted from existing 'one-size-fits-all' approaches. Existing interventions have been criticised for their lack of user involvement and for being policy driven 'top-down' approaches rather than being determined by the needs and priorities of stakeholders (Bailey et al. 2017).

Although there is significant overlap with the experience of different ethnicities of subfertile women, findings from this dissertation revealed how the sociocultural experiences of women from lower socioeconomic backgrounds or African descent present a unique barrier, for instance, from participation in meaningful activities or maintenance of social networks. If they had a counsellor of the same country of origin, they may feel hesitant disclosing details due to fear of experiencing the same stigmatisation they may have faced (or are facing) within their family or community. On a similar note, African women may encounter racial bias from non-African specialists as anti-racism training is not apart of the curriculum. It is important to note that homogenising African communities into one group based on continent or even country of origin is problematised by the complex intersectionality of their identities. Studies suggest that both Black and White people may be subject to implicit racial biases. For example, a US study demonstrated the social biases reflected in the implicit racial stereotypes of Black people where preference for White people and against African Americans were observed among African American as well as White medical students and doctors (Haider et al. 2011; Weinstock et al. 2012; Sabin et al. 2009). Studies have shown that a physician's racial biases against particular racial and ethnic minority patients is significantly related to the quality of care they provide to their patients (Weinstock et al. 2012). As a result, patients may feel their access to equitable, good quality care is restricted in terms of scope and depth even amongst those who may share the broad ethnic designation usually assigned.

Additionally, in a more recent pilot survey conducted by HFEA in 2018 that aimed to assess patient experience of fertility services highlights that amid deep NHS rationing, 62% of those paying for IVF felt they paid 'more than expected' for their treatment (HFEA 2018; Telegraph 2018). Additionally, the rigid working patterns involved in manual employment have previously been associated with greater perceived difficulty in accessing healthcare and are likely to affect immigrant communities differently given the varying employment patterns by ethnicity (Sweeney et al. 2015; Field & Briggs 2001). Labour peer Lord Winston commented that the biggest change in the service is its increasingly driven commercial market that has resulted in costly treatment and consequently, inequalities (Telegraph 2018). Commentators suggest the introduction of general management, the development of fund-holding general practitioners and the establishment of the internal market within the NHS by Conservative Prime Minister Margaret Thatcher and her successors sparked the start of this consumerist development (Mold 2013). From the 1980s onwards, as market models gained more influence on the provision of health care, further repositioning of the patient resulted in conflict between the individual and collective views of the patient. It appears that individual patient choice has edged out collective patient voice. Although the demands of the individual patient, may be irreconcilable with all patients, whether there is enough shared similarity between them to allow the merging of subgroups under a broad category is an open question (Mold 2013). The findings of this systematic review suggest that interventions must be specifically designed to ensure they meet the needs of

subfertile women with access difficulties or sociocultural barriers and support them manage the psychosocial consequences of subfertility itself. Although there is a paucity of research into the development and robust evolution of psychosocial interventions for different ethnicities, religious and socioeconomic background of subfertile women, interest in this research field is growing rapidly (Bailey et al. 2017).

Findings also indicated that perceived quality of care was affected by the strength and quality of specialist-user relationship (Sweeney et al. 2015). This relates to prior research with highlighting how trust, satisfaction, the perceived time available for managing the priorities and continuity of care influences the receptiveness of recommendations about care from doctor, particularly in minority ethnic patients (Sweeney et al. 2015; Carpenter et al. 2009).

4.3 Strengths and Potential Limitations of this Review

A strength of this dissertation is that a systematic method was used to find, summarise and interpret existing qualitative research in relation to a specific question. Although the themes stay close to findings of individual studies, by drawing the findings together an overall interpretation of the literature in relation to longer-term need was developed. Analysis went beyond a descriptive summary of study findings by identifying the implications of the synthesis for understanding and responding to the longer-term needs of such service users (Appendix P Table 15.0). Reflecting on the analytical themes here, an area which may have required further investigation in the synthesis is the concept of temporality; how longer-term needs exist within or have a relationship with time. This may be a vital explanatory concept in terms of being able to better appreciate the ways the needs of subfertile women accessing ART across Africa and Europe may change or evolve over time and how sociocultural issues including strained social interactions influences how needs are experienced. For example, the way womens' needs may change over time should also be appreciated. This dissertation highlighted this in the creation and maintenance of support networks (Appendix P Table 15.0).

A limitation of this synthesis is that this temporality was not systematically explored across studies. However, some inferences regarding this concept may be made. For instance, the struggle subfertile women of African descent experienced whilst coming to terms with their loss of social status was evident across a number of studies which included participants at a range of timepoints after diagnosis (Dierickx et al. 2019; Dierickx et al. 2018; Fledderjohan 2012; Weinger 2009; Mogobe 2005; Mariano 2004; Hollis 2003; Yebei 2000; Gerrits 1997) (Appendix P Table 15.0).

Further areas of limitation include that the quality of the synthesis is limited by the quality and reporting of the original studies (Dixon-Woods et al. 2004; Campbell et al. 2003). For example, full development of the 'availability' theme was limited by the lack of contextual information in the reporting of the UK primary studies (Bailey et al. 2017; Roberts & Franklin 2004) (Appendix P Table 15.0). Furthermore, the results of the quality assessment highlighted the lack of reflexivity in some of the included studies. If the researcher has not critically reflected how their own position within the research may have influenced the conduct or findings of the study, it is difficult to evaluate levels of researcher bias in study findings (Berger 2015; Jootun et al. 2009) (Appendix P Table 15.0). A third limitation is the difficulty assessing publication bias. It is possible there is a bias towards publishing studies highlighting the adverse experiences of subfertile women experience accessing ART as opposed to those highlighting more positive experiences (Redshaw et al. 2006; Garcia et al. 1998). This may be indicative of the kind of groups experiencing less difficulty accessing ART being over-represented in research (Appendix P Table 15.0).

4.4 Conclusions

This synthesis highlights the significant and continuing need for longer-term support experienced by subfertile women of different ethnicities across Europe and Africa accessing ART. Services design may fail to currently

address access issues to ART and the psychosocial consequences of subfertility and may not enable women of different ethnicities to successfully manage these difficulties within this context. The concept of candidacy as a means to understand access to healthcare services by vulnerable groups is a useful framework for interpreting these findings (Sweeney et al. 2015; Dixon-Woods et al. 2005). They emphasise that eligibility for medical attention and intervention is a joint 'negotiation between individuals and health services' (pp.42). In this case, candidacy or eligibility for ART is proposed by the healthcare provider. Engagement may be dependent on accepting that the provider statement of eligibility is consistent with their own perceptions of eligibility and worth the expense incurred. As this review has demonstrated that different beliefs about subfertility itself determine what women do when faced with it and what support they can enlist, doing this may prove difficult for Africans. Whilst navigating the access and the treatment process, their response may be influenced by fear of diagnosis; language and communication difficulties; scheduling conflicts from work demands; religious and cultural proscriptions; social strain within their communities as well as problems relating to confidence and trust with care. Extending understanding of how women, who are often under-represented with ART and research, adapt to the adversity they experience may aid clinicians in offering more culturally informed interventions (Bailey et al. 2017; Greil et al. 2010).

Implications for Practice, Policy and Future Research

Future research should explore the possible components of a longer-term term care intervention that is patient-centred for different ethnicities of subfertile women across Africa and Europe. Few studies explored how subfertile women manage sociocultural barriers during and after ART is required to further understand adaptation and adjustment during this time period and inform subsequent care strategies. Research comparing those who have temporarily and permanently stepped away from ART may better illuminate how resilience manifests among women and influences their decisions to end or continue treatment. Future research also ought to widen data collection within each ethnic community to include the views of community members who are more isolated from health and community support services and potentially have different perspectives from those that are represented in this systematic review. This is important because this review has demonstrated that beliefs about subfertility itself influence the decisions of different ethnicities of women and affect the support they can enlist.

Clinicians may also draw on these findings to highlight the importance of maintaining the non-fertility aspects of their life and assess their resources for ART in order to prevent further depletion in their physical and psychological well-being. Fertility services should aim to support this by allowing women to take an active role in their treatment and be transparent in decision-making processes. Offering consultation about various evidence-based holistic methods such as indigenous herbalism and spiritual support may help integrate women's need to gain control over their treatment and limit their exposure to exploitative services offering expensive or redundant solutions (Bailey et al. 2017; Clark et al. 2013). The incorporation of local disease classifications into public health messages may address former exclusion of folk illnesses in public health practice, resolve communication constraints with users and potential delays accessing ART. Furthermore, systematically harnessing patients' voices into clinical operations may, as with co-design or other forms of patient engagement, hold greater promise for meaningful improvements to the patient experience than would incident reporting or root cause analysis-like assessments of patient complaints of ART (Liu et al. 2019). However, it is important to highlight that attributing treatment choice to miseducation does not comprehensively represent their pragmatism considering existing structural inequalities and lack of integrated care. For this reason, this review suggests that while individuals should have the reproductive right to access publicly funded services, alternative forms of parenting and social identity should be publicly promoted for subfertile men and women across Africa and Europe.

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