Infertility in South Africa: women’s reproductive health knowledge and treatment-seeking behaviour for involuntary childlessness

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BACKGROUND: Infertility is a major reproductive health problem in Africa. This paper presents the findings of two studies which focus on the knowledge that infertile women have about fertility and the causes of infertility, their treatment-seeking behaviour and their expectations of an infertility clinic. METHODS: A total of 150 infertile women from a culturally diverse, urban community in South Africa participated in the two studies. Both qualitative and quantitative research methods were applied using in-depth, semi-structured interviews and structured questionnaires. RESULTS: The women who participated had little knowledge about human reproduction and modern treatment options for infertility. They were highly motivated to find treatment and accessed both traditional and modern health care. Treatment barriers within modern health care were identified. CONCLUSIONS: The importance of health education and counselling is recognized, and both need to be integrated into infertility management, particularly in the developing world. The introduction of clinical guidelines is recommended in order to overcome treatment barriers and improve the delivery of health services.

Key words: Africa/health-seeking behaviour/health services/infertility/traditional health care

Introduction

Infertility, defined as the inability to conceive after 1 year of regular intercourse, is said to affect 8–14% of couples (Emslie et al., 1993; Bhatti et al., 1999). In Africa, infertility is a major reproductive health problem with regional prevalence rates of 30–40% (Leke et al., 1993). Infection, which is the commonest cause of infertility, affects the physical health of both men and women. Women in particular, also commonly suffer from severe negative social consequences such as stigmatization, ostracism, abuse and economic deprivation (Alemnji and Thomas, 1997; Gerrits, 1997; Sundby, 1997). The effective management of infertility therefore has considerable impact on reproductive health in Africa.

Groote Schuur Hospital Infertility Clinic is one of the few tertiary public health institutions in South Africa delivering a Reproductive Medicine Service focusing on the needs of the indigent community. In almost all parts of South Africa, local communities consist of several heterogeneous population groups. In Cape Town, three major racial groups (black, coloured and white) and three major language groups (Xhosa, Afrikaans and English) are present. There is considerable overlap between racial and language groups, with black people speaking predominantly Xhosa and English, and coloured and white people speaking mostly English and/or Afrikaans. The various racial groups consist of further subgroups which often differ in their culture and religion. The Reproductive Medicine Service offers modern infertility treatment ranging from endoscopic reconstructive tubal surgery to assisted reproductive techniques. Each year nearly 1000 couples are referred to this facility, most commonly from the local public primary care services or from general practitioners. Although the large number of referrals reflects the need for treatment, the effectiveness of the service is currently compromised by a high patient default rate (~65%).

This paper presents the findings of two studies which were undertaken in order to gain insight into women’s health-seeking behaviour and to explore barriers to modern infertility treatment. It was anticipated that the results of these studies would contribute to the development of future interventions aimed at improving the delivery of modern infertility services to women from developing communities and culturally diverse population groups. The two studies combined qualitative and quantitative research methodology. The qualitative approach facilitated insight into complex human behaviour and was complemented by quantitative measures.
Patients and methods

The study population of the qualitative study consisted of 30 women presenting to a tertiary hospital infertility clinic for an initial appointment (referred to as Group A). In order to ensure a study sample which broadly represents the culturally diverse population served by this clinic, informants were selected from four groups of women: 12 black Xhosa-speaking women, six women from the Muslim community, six coloured or white women and six patients whose economic situation meant they were classified as ‘private patients’ (patients who have medical insurance or who have a monthly family income above a certain level) and paid a higher fee for the services received. Analysing differences between the four population groups was not an aim of either of the two studies.

Qualitative methods were employed using semi-structured, in-depth interviews. All interviews were held at our Infertility Clinic prior to the women meeting with any member of the medical team. Women were interviewed alone, without their partners. All interviews were conducted by one multilingual professional nurse who was not involved in the service and who was trained in in-depth interviews and counselling. The interviews were held in the women’s first language (Xhosa, English or Afrikaans) and were taped, transcribed and translated into English. An interview guide was developed which allowed for the exploration of knowledge of human reproduction, the causes of infertility, health seeking practices and expectations of an infertility service. Further questions focused on the psychological and social experience of infertility. This paper presents the findings on women’s reproductive health knowledge and treatment-seeking behaviour. The data pertaining to the psycho-social experience of involuntary childlessness is reported separately (Dyer et al., 2002). Content analysis was used by coding each interview into common themes.

In the quantitative study, 120 women were recruited consecutively at their initial visit to the infertility clinic (referred to as Group B). Personal interviews were held using a structured questionnaire which obtained information on demographic data, women’s understanding and expectations of modern infertility treatment and their previous attempts of obtaining treatment. All questionnaires were administered by one multilingual professional nurse trained in research skills. Women were interviewed alone and in the language of their choice.

Informed consent was obtained from all women in both studies. Women were assured that declining to participate would in no way influence their management. The studies were approved by the Ethics Committee of the University of Cape Town, Faculty of Health Sciences.

Results

Demographic information

In Group A, the mean age of the women interviewed was 31.5 years (range 21–41). Twelve women presented with primary infertility. Of the 18 women with secondary infertility, six had no living children and only three had a child in their current relationship. None of the informants had more than one child. Twenty-six women were married, two were in the process of marriage and two said that they could only marry once they had conceived. The mean duration of infertility was 4.8 years (range 1–15). The mean age of women in Group B was 29.2 years (range 21–40). Further demographic data of group B is summarized in Table I. Of the 37 women who had at least one child, 14 (37.8%) had no child in their current relationship.

All women who were approached for the qualitative study agreed to participate. In the quantitative study, 126 women were approached of whom six refused to enter into the study. Two women said that they did not have time for the interview, one suggested that her husband should be interviewed as he seemed to be the infertile partner and three husbands prevented their wives’ participation.

Knowledge of human fertility

Participants in Group A had scant knowledge about the basic principles of human reproduction. Several women stated that their only knowledge was that intercourse was required for conception. Others explained that, ‘something was mixing in the woman’s body’ was ‘working inside,... causing a lot of changes’ and subsequently grew inside the body into a baby. Women described ‘seeds’, ‘sperms’ and ‘eggs and sperms’ ‘mixing’. Most women were aware of their limited knowledge and many indicated their wish to know more. Only two of the 30 women interviewed made some reference to the Fallopian tubes as the site of fertilization and a passage through which the egg moves. None of the participants could give a simple summary of the biological events leading to conception. For two reasons, women’s knowledge of fertility and causes of infertility was not re-evaluated in the quantitative study. Firstly, poor knowledge was a consistent finding in Group A. Secondly, the researchers considered a qualitative approach to be more suitable for gaining insight into women’s reproductive health knowledge when compared with a quantitative approach.

Knowledge of causes of infertility

Approximately half of the informants said they did not know what might cause infertility (Group A). Despite stating this lack of knowledge, most women attempted to explain their involuntary childlessness. Common explanations included the concept of ‘blocked tubes’, ‘weak sperm’, abnormal menstrual periods and previously used family planning methods. Sometimes these explanations were based on a medical diagnosis given to the patient, as in the case of a patient who had bilateral ectopic pregnancies. More often, however, patients had developed their own constructs. As one informant said: ‘Sometimes I could feel my tubes were blocked. I would have pains. I could feel the channel through which the blood is
travelling is small, because it is painful.’ Several women linked tubal blockage to the previous use of hormonal contraception. The fact that medical information often failed to clarify the true cause of infertility is demonstrated in the following narrative: ‘When he [her husband] was a child, when he was 3 years old, he was playing with his twin brother. They were playing on the bed so he fell and knocked his testicles up into his body. He had to have an operation to pull them back down. Now what the doctors are telling us is that they are underdeveloped.’ The clinical diagnosis was undescended testis—for the patient a minor fall was interpreted as the cause of infertility. As a result, the husband’s mother blames herself for not preventing the accident.

Many women were concerned about a ‘dirty womb’. Women came in the hope that they would be ‘cleaned’ either through medication or a ‘womb scrape’ (dilatation and curettage). One woman felt reassured by a normal Pap smear. She explained that this meant that ‘the mouth of the womb was open’ and thus able to conceive. A wide range of other possible explanations was given. Women looked for reasons in their lives which could explain their involuntary childlessness. These included, amongst others, sexual techniques, coincidental medical conditions (such as epilepsy), alcohol abuse and religious reasons. ‘Maybe I am being punished for having sex before marriage,’ one woman said. Nearly half of the black women considered evil spirits or witchcraft to be a possible cause of childlessness.

Women’s expectations of the infertility service

All women were asked what expectations they had of the infertility clinic. In both studies answers to these questions centred around three issues: The hope to conceive, the hope to receive information and uncertainty, i.e. not knowing what to expect. Approximately one-third of the women in Group A expressed high expectations of success. These women were confident that the clinic would be able to resolve their infertility and often felt ‘curious’ and ‘excited’. Sometimes the expectations were unrealistic, especially as far as time to conception was concerned. More than one informant expressed her hope to leave the clinic pregnant after the first visit. Nearly half of all women in Group A expressed uncertainties and ambivalence. Women often said they did not know what to expect. Some women expressed doubts as to whether the clinic was able or willing to help them. Not surprisingly, these women often felt anxious. ‘I was worried, anxious what will be done to me?’ one informant told us. For some couples uncertainty seemed to create a barrier: ‘I asked my husband... but he did not want to come. I suppose he is shy to come. He doesn’t really know what is expected of him.’

These results were corroborated by the quantitative analysis, in which 54 of the participants (45%) felt that they would definitely conceive by attending the clinic, 55 (45.8%) thought that they might fall pregnant and 11 (9%) said they ‘did not know’. Women’s expectations regarding the duration of infertility treatment are listed in Table II. Only 11 participants expected the treatment to take >1 year.

The importance of information became particularly evident in Group A. For 10 women this seemed to be the most important aspect of their first visit to the clinic. These women were worried about their lack of knowledge and of not knowing if, when and how they could conceive. One informant asked, ‘Will the doctor answer all my questions?’ Another woman said, ‘I need some answers and some facts, if I can have babies or not. I don’t expect any miracles, I just need some answers.’

When women were asked in more detail about various aspects of infertility management (e.g. investigations, treatment and cost) it became apparent that the majority of patients in both groups did not know what to expect. There was consistency between the qualitative and the quantitative data. Many women emphasized that they wanted to be ‘tested’ and ‘properly examined’ but had little further information as to what this would entail. ‘They must examine us and make us fertile... (in) the ways they have learnt’ one informant explained (Group A). Several women wanted to be ‘cleaned’ and others expected to receive medication or some form of treatment to make their husband’s sperm ‘stronger’. A few had obtained information (via television, radio, friends or lay magazines) about modern infertility treatment, but the qualitative study demonstrated how this knowledge was often incomplete and distorted. The following descriptions probably relate to artificial insemination with donor sperm, artificial insemination with husband’s sperm and IVF: ‘Maybe I am fertile and he is not and then they take another man’s sperm, if I am not [fertile] then they take another woman’s’; ‘They take the husband’s, what is it called, and they plant it in the woman and it goes through and the woman falls pregnant’; ‘I know that they take blood, he must give his sperm. They take an egg from me [and] mix it with the sperm and then they freeze it. Then I must come in and push it in with a needle. After that I must see what happens, if I get pregnant or not.’

Similar concepts emerged following the quantitative analysis of women’s understanding of modern infertility treatment (Table III). These included the concept of having to be examined (‘checked’) and treated ‘as necessary’, the concept of requiring ‘cleaning’, the request for specific infertility treatment (i.e. artificial reproduction techniques or reversal of

| Table II. Expected duration of infertility treatment |
|--------------------------|----------|--------|
| Duration                | n        | %      |
| ≤1 month                | 9        | 7.5    |
| 2–6 months              | 49       | 40.8   |
| 6–12 month              | 51       | 42.5   |
| >1 year                 | 11       | 9.2    |

<table>
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<th>Table III. Women’s concepts of modern infertility treatment</th>
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<tr>
<td>Concept</td>
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<tr>
<td>Of being ‘checked’ and ‘treated’</td>
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<tr>
<td>Of specific interventions</td>
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<tr>
<td>Of requiring ‘cleaning’</td>
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<tr>
<td>No concept</td>
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tubal sterilization) and a group of women who had no apparent concept at all of what treatment might be offered.

**Motivation for treatment**

As a qualitative approach was considered to offer better insight into women’s motivation for treatment, no quantitative data was collected. The majority of informants were highly motivated. Despite the apparent lack of knowledge as to what the treatment would entail, women said they were prepared to ‘do anything’, ‘do whatever it takes’ and ‘go the whole way’. For some women this willingness to comply appeared to be unconditional. These women were prepared to undergo treatment for any length of time and cover costs without question. ‘I will do anything. No matter how much it will cost. I will do everything in my power.’ Some women had financial concerns but tried to overcome these: ‘I will save, believe me I will save,’ one woman promised. ‘I don’t know if the hospital will help me because I lack finance... I will make a plan, I am sure I will make a plan... because I desperately want a child,’ another one informed us. For several other informants, compliance was linked to the expectation that they would eventually conceive: ‘I will do what I must do as long as I will get a child.’

A small group of women came for treatment in order to please their husbands. These women showed the same level of motivation as most of the other informants. ‘I am trying to see what I can do. I do not want him to point a finger one day and say you did not even try to see if we can get babies. That is why I am going doctor in and doctor out,’ one informant explained.

Only very few women expressed reservations regarding the treatment. They felt that they might lose patience after a period of time, although this period could extend to a year or two. Only one woman stated clearly that if she had to wait for a long period of time or pay a lot of money then she would rather stay without a baby. This woman already had a healthy son from her current relationship.

**Access to health care**

All women in both studies had actively tried to access medical treatment. According to the results of the qualitative study, women appeared to have taken the initiative to access modern health care in almost all instances, although several husbands ‘came along’ to the doctor or had even undergone some clinical examination. Most women had sought medical help from an environment they were familiar with: their local clinics, ‘private doctors’ (general practitioners) or gynaecologists. Only very few women had tried to obtain information on doctors or clinics with special expertise and had then arranged to be referred accordingly (Group A).

The interviews in Group A showed that women had different experiences with the health system. All of the six private patients and one non-private patient had previously received specialist infertility care in the private health sector. The reasons why these women now attended a public hospital included disappointment with the previous treatment, the successful treatment of a friend at our institution, financial constraints and referral by a specialist for further infertility management. Several women had been referred to us after appropriate management by a private general practitioner or a primary health care worker. However, many other informants had experienced barriers, the most common being ineffective primary care, particularly in the public health sector. Several women had been told that ‘their womb was dirty’ and had received ‘tablets for cleaning’. Others had been informed that nothing was ‘wrong’, or that pregnancy would occur ‘naturally’. Some women said that they had never been examined and criticised the doctors for what they perceived to be a lack of care. As one informant related, ‘The problem is that doctors say that falling pregnant will happen on its own. They don’t do physical examination, they just talk to me, write it down and tell me to go to the chemist for pills... You see, when you want a child...what can a painkiller do?’

One woman, after going to doctors for 10 years without a diagnosis being established, went to a traditional healer as she thought that the devil spirit was hiding the problem from the doctors. Most women persisted—often over several years—in their attempt to get help by going to ‘other doctors’ and looking for ‘other advice’. Very few women said that there was a time when they ‘just gave up’ and ‘had enough’.

The quantitative analysis largely confirmed these findings. Over 25% of the study population had tried to obtain help for >5 years (Table IV). Twenty-one percent of women had tried to get help from sources other than medical practitioners (Table V). In order to assess if transport to the infertility clinic was a possible treatment barrier, women were asked about their transport to Groote Schuur Hospital. None of the patients lived within walking distance and the majority was dependent on public transport (82%). Most patients said that they could reach the hospital within 1 h of travelling. All but one of the participants were not concerned about transport, even if clinic visits were required regularly.

**Use of traditional health care**

Several women (particularly black women) had consulted a traditional healer (16.6% of Group B). The semi-structured interviews with women in Group A offered a level of insight

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**Table IV. Time period spent on seeking infertility treatment**

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<th>Time period</th>
<th>n</th>
<th>%</th>
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<tr>
<td>&lt;2 years</td>
<td>20</td>
<td>17.7</td>
</tr>
<tr>
<td>2–5 years</td>
<td>63</td>
<td>55.7</td>
</tr>
<tr>
<td>&gt;5 years</td>
<td>30</td>
<td>26.6</td>
</tr>
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Note: seven patients could not state the time period

**Table V. Sources of health advice**

<table>
<thead>
<tr>
<th>Sources accessed</th>
<th>n</th>
<th>%</th>
</tr>
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<tbody>
<tr>
<td>Medical doctor</td>
<td>120</td>
<td>100</td>
</tr>
<tr>
<td>Traditional healer</td>
<td>20</td>
<td>16.6</td>
</tr>
<tr>
<td>Spiritual healer</td>
<td>10</td>
<td>8.3</td>
</tr>
<tr>
<td>Homeopathic doctor</td>
<td>2</td>
<td>1.6</td>
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into traditional health care. These women had usually received some ‘herbs’ or ‘medicine’ to drink in order to be ‘cleaned’. Others were told that a jealous woman (previous girlfriends or a mother-in-law) had bewitched them. As one informant explained: ‘We went to the witch doctor and he explained to me that another woman at home had bewitched me. If I sleep with him (husband) ... everything comes out’. Another woman was informed she was possessed by ancestors and that she would have to become a traditional healer. Reference has already been made to the woman who feared that witchcraft prevented the doctors from finding a cause for her childlessness.

Discussion

Public health planners have recognized the importance of being informed about the knowledge and perceptions which people hold regarding health and illness, causes of disease and possible remedies. Particularly in non-Western countries, the local explanations and concepts of health and disease may differ from the formal biomedical health model which underlies modern medical care in both the developing and the industrialized world (Atkinson and Farias, 1995). The results of our studies clearly reflect such differences.

Our findings highlight several important factors that are likely to influence women’s responses to infertility treatment. A cardinal factor was the amount and quality of information available to patients. Our results demonstrate that women had essentially no knowledge about the basic principles of human reproduction. Similarly, most women had a poor understanding of possible causes of infertility. Furthermore, the qualitative aspect of our studies highlighted the frequent discrepancy between biomedical information rendered by patients and their personal concept of this information. In other words the concept that women may hold of tubal blockage may differ from modern medical thinking. Health care workers should be aware of the level of knowledge of their patients and of the differences between biomedical and lay concepts. Such differences are particularly important as they influence health-seeking practices (Atkinson and Farias, 1995). The most striking deviation from the modern biomedical model in this study was the belief in witchcraft and visits to the traditional healer, but this did not necessarily create a conflict between modern and traditional health care, as several women tried to seek help from both sectors.

Women were also lacking information about modern infertility management. Such a lack of information is likely to cause or contribute to anxiety, which in itself can create a barrier to treatment. The fact that many women expressed their need for information was an important finding of our study. It demonstrates that, particularly in the developing world, infertility treatment has to encompass information, health education and counselling. The results of our study indicate that such interventions are likely to help women in accessing effective medical care, comply with treatment and deal with their childlessness. Unfortunately, public health services in this country commonly turn infertile clients away without counselling or investigations as they lack the resources for infertility treatment.

Our results are in keeping with the few other studies undertaken in African countries. A recent review (Bambra, 1999) on the current status of reproductive behaviour in Africa emphasized the lack of adequate knowledge about sexuality and reproductive health, particularly amongst women. The low educational level and literacy rates in Africa were thought to compound this problem as they created barriers to reproductive health awareness campaigns (Bambra, 1999). Following an analysis of the burden of reproductive organ disease in rural women in Gambia, Walraven et al. concluded that an increase in community knowledge about reproductive health and disease is urgently required (Walraven et al., 2001). A study undertaken in Mozambique indicated that the explanations infertile women could give for their childlessness originated more often from the traditional healers than from hospitals (Gerrits, 1997). In a further report from the Gambia, women suffering from involuntary childlessness were largely unaware of the causes of infertility (Sundby, 1997).

Information is essential, as it is the basis for treatment as well as for prevention. Such information has to be delivered in a sensitive way. It needs to take cognisance of existing concepts as well as of women’s concerns regarding the reasons for their infertility. Our studies offer insight into these concepts and concerns. Complicated medical terminology, based on the assumption that the client is familiar with the biomedical principles of human reproduction, may deter rather than encourage clinic attendance. Health care workers need to be aware that they are operating in a domain of sensitive personal experience which is often considered private in African cultures (Bambra, 1999).

Women actively looked for a solution to their problem and often showed great persistence in trying to access help. Given their lack of knowledge about modern treatment options and how to access these, women were particularly dependent on the skills of individual doctors in terms of management and referral. Our results indicate a possible need for the improvement of infertility management at primary care levels, especially in the public health sector. The fact that >25% of women in Group B tried to access infertility treatment for >5 years has to be viewed with concern. A follow-up study is currently being conducted in order to evaluate barriers to effective primary care management and to develop management guidelines. The value of clinical guidelines in the improvement of primary care management of the infertile couple has been demonstrated (Emslie et al., 1993). Modern infertility services also need to take cognisance of alternative treatment facilities, both medical and non-medical. Several women in our study had accessed traditional healthcare. The importance of traditional healers in the management of involuntary childlessness has been highlighted in other studies. In Mozambique, childless women visited traditional healers more commonly and undertook longer journeys and paid more money in order to do so than to access modern health care (Gerrits, 1997). Sundby studied traditional and modern health care of infertility in the Gambia and emphasized the need for collaboration between modern and traditional healers (Sundby, 1997). This would facilitate referral of infertile clients to the formal health system,
while spiritual and cultural needs could be addressed through alternative care structures.

The vast majority of women in this study were highly motivated to undergo infertility treatment. The willingness to ‘do anything’, without knowing what this might entail, is likely to reflect the situation of many women from disadvantaged communities. They are often trapped in a condition which elicits social disapproval, which they cannot explain and for which they do not have a solution. The psychological and social consequences of infertility have been extensively studied in the developed world. Far less attention has been paid to women’s experiences with infertility in the developing world. The few reports that do exist indicate a high prevalence of stigmatization, ostracism, abuse and divorce of infertile women in Africa (Bergstroem, 1992; Alemnji and Thomas, 1997; Sundby, 1997). Women in our own study (Group A) reported a high level of social pressure (S.J.Dyer, N.Abrahams, M.Hoffman and Z.M.van der Spuy, unpublished data). In the setting of highly motivated clients who are actively seeking a solution to their problems, the lack of compliance with modern infertility management, as experienced in our clinic, has to be viewed with great concern. Although this study has identified some barriers to compliance, further studies will be needed in order to improve the delivery of existing healthcare facilities to men and women from African communities.

Given the heterogeneous study population, it may seem tempting to look for differences between the various groups of women in order to focus possible interventions. However, this study aims at heightening the awareness of health professionals towards the needs of women from different social and cultural backgrounds. We are concerned that placing patients into ‘categories’ will be detrimental to this process. Instead, we should look for interventions which are sensitive and flexible enough to accommodate all groups of women from our community. Given the history of South Africa, this is of particular importance in our country.

Our study was undertaken among women presenting to an infertility service for treatment and who agreed to participate in the research. Care has to be taken not to extrapolate our findings to all women suffering from involuntary childlessness. We share this caveat with many other studies of the social and psychological correlates of infertility which usually draw volunteers from infertility clinics or self-help groups (Greil, 1997). It is likely that women who do not wish to be interviewed and particularly those who do not seek treatment may differ in their experiences and future research should be directed at this group of women (Greil, 1997).

In conclusion, these two studies, undertaken on infertile women from a culturally diverse urban South African community, have highlighted certain factors which contribute to women’s experiences of infertility and influence their interactions with modern health care facilities. The combination of qualitative and quantitative research methodology facilitated the understanding of complex human behaviour and experiences, whilst applying some quantitative measures to our results. Where comparisons could be made with other studies from Africa, similarities were found. This helps to corroborate the experiences of infertile women in this part of the world. The lack of knowledge and the need for information were important findings of our study. Our results indicate a need for health education as part of both infertility management and prevention. This need appears to be of such overwhelming importance that information and counselling is essential even if treatment, due to lack of resources, cannot be offered. The introduction of clinical guidelines is recommended in order to improve primary care management and referral to tertiary care. Cultural variations in the experience of infertility exist, but remain under-researched. The need for further research on the experiences of infertility, the delivery of infertility services and the role of the health care provider is recognized (Greil, 1997). Nowhere is this need greater than in the developing world, where a woman’s status is often determined by her reproductive success.

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