

# ‘Men leave me as I cannot have children’: women’s experiences with involuntary childlessness

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**BACKGROUND:** This study explores the concerns and experiences related to involuntary childlessness of infertile women living in a diverse cultural urban community in South Africa. **METHODS:** In-depth interviews were conducted with 30 women seeking treatment for involuntary childlessness. Women were interviewed at the time of their first visit to an infertility clinic in a tertiary referral centre. **RESULTS:** All women verbalized intense emotions about their involuntary childlessness. In addition, a large number of women experienced negative social consequences including marital instability, stigmatization and abuse. **CONCLUSIONS:** These findings demonstrate that infertility can have a serious effect on both the psychological well-being and the social status of women in the developing world. Furthermore, the study provides insight into the cultural context of involuntary infertility in South Africa. The delivery of good infertility care in a community requires awareness of the implications of infertility and insight into the context in which these occur. Since many of the negative social implications of infertility are probably rooted in low status women in the developing world, effective intervention will ultimately require social, economical and political changes.

*Key words:* Africa/infertility/psycho-social factors/reproductive health

## Introduction

Despite a high population growth rate in Africa, infertility remains a major reproductive health problem. Prevalence is high and the underlying pathology frequently affects women’s physical health. In a study undertaken by the World Health Organization the cause of infertility in the African countries could be attributed to infection—secondary to sexually transmitted diseases and pregnancy complications—in >85% of women (Cates *et al.*, 1985).

Infertility is, however, not solely a medical problem. The psychosocial consequences of infertility have been extensively studied and the occurrence of stress, anxiety, depression and marital difficulties, as well as other symptoms, have been reported (Berg and Wilson, 1990; Downey and McKinney, 1992). Until recently studies have focused predominantly on patients in industrialized countries while the experience of infertility in the developing world has received comparatively little attention (Ericksen and Brunette, 1996; Papeen *et al.*, 2000; van Balen and Gerrits, 2001). After the International Conference on Population and Development in 1994 and the World Conference on Women in 1995, this focus has gradually shifted as the poor status of reproductive health in the developing world and the difficulties in delivering effective reproductive health care in poor-resource areas are increasingly

appreciated (van Balen and Gerrits, 2001; Walraven *et al.*, 2001).

Central to the delivery of effective infertility care is an understanding of the experiences and implications of involuntary childlessness and of the religious and cultural context in which these experiences occur. Although studies are emerging which provide such insight, the overall lack of information and the need to increase awareness of both policy makers and the public have been recognized (van Balen and Gerrits, 2001; Walraven *et al.*, 2001).

This study reports on the experiences, concerns and behaviour of infertile women from a diverse urban community in South Africa. It was aimed at raising the awareness of policy makers and healthcare providers in two ways: we hoped to increase sensitivity to cultural needs/demands in the delivery of reproductive health care and also to improve knowledge about the potentially serious implications of infertility in South Africa. In order to capture the complexities of the psychological and social phenomena studied, qualitative research methods were utilized. This approach avoids the more rigid format for gathering quantitative data, a format which limits the ability of the respondent to reply and prevents exploration of unexpected topics (Berg, 1994). The value of qualitative methodologies in the evaluation of the psychosocial implications of infertility

has been increasingly recognized (Berg, 1994; van Balen and Visser, 1997).

The study was conducted among women who presented to a tertiary level infertility service in the public health sector. In South Africa the public health system offers health care at low cost to all patients who cannot afford private facilities. Patients who can access private care may still enter the public health system, but will pay higher fees. The public health system is structured into primary, secondary and tertiary levels of care. Although some preliminary infertility evaluation is undertaken at primary and secondary level facilities in the local setting of Cape Town, couples who present with involuntary childlessness are managed predominantly in the tertiary service. This implies that the women in our study had no infertility treatment prior to their interviews, unless they had access to private health care.

### Materials and methods

This study was undertaken at Groote Schuur Hospital in Cape Town, South Africa. Further investigations were performed on the same sub-group (Group A) of a study population discussed in a concurrent publication (Dyer *et al.*, 2002). Women from the local community were recruited to the study. Shaped by both colonization and the apartheid system, the community of Cape Town consists of three major racial groups. Currently approximately half of the Western Cape population is coloured (mixed ancestry), while white and black people each make up one-fifth of the population. The comparatively low number of black people is a legacy of the apartheid policy which prevented black South Africans from residing in the area. There are three major languages in this region: black people speak predominantly Xhosa and English and coloured and white people speak mostly English and/or Afrikaans.

Details regarding the selection of participants and collection of data have been reported (Dyer *et al.*, 2002). Briefly, thirty women who presented for their first visit to the infertility clinic were interviewed. They comprised four broad groups of women: 12 black Xhosa-speaking women, six women from the Muslim community, six coloured or white women and six women whose economic status meant they were classified as 'private patients' and paid higher hospital fees. This selection of informants from various groups of women was performed in order to achieve a study sample representative of the population served in our clinics. It was not aimed at analysing differences between the population groups.

Qualitative research methods were applied in order to gain insight into the complex experiences of infertility. Data were collected by means of in-depth semi-structured interviews held in each woman's preferred language (Xhosa, English or Afrikaans). All interviews were held at the infertility clinic prior to the women meeting with any member of the clinical team. Women were interviewed alone. Partners were excluded as it was anticipated that abuse may be part of women's experiences and the presence of a partner might inhibit communication. All interviews were conducted by a professional nurse who had in-depth interview and counselling training. The discussions were taped, transcribed and translated into English.

An interview guide was developed and questions focused on women's psychological and social experiences of infertility. The interview guide was open-ended and allowed new topics to be explored as they revealed themselves during the interview. The

interview transcripts were analysed inductively using grounded theory. Briefly, data analysis and presentation according to the principles of grounded theory include a systematic process of data coding consisting of open, axial and selective coding. In the initial process of open coding, the data is broken up into 'categories' (containing recurring concepts) and subcategories. This is followed by axial coding in which relationships between categories are explored and contexts and causes of behaviour identified. The process of axial coding is mostly reflected in the Results section but also in the Discussion of this paper. Finally, selective coding refers to the process of drawing up a narrative report (Discussion) which integrates the categories of axial coding and presents conclusions (theories) which are 'grounded' in the original data (Creswell, 1998). The narrative report of qualitative research should provide coherence and structure to the data while preserving the narrative of the individual participants (Berg, 1994; Ritchie and Spencer, 1996). In this paper the headings (categories) of the Results section offer such structure. The embedded quotes (used in the Results section) preserve the original narrative and provide specific evidence in the words of the informants to support the information which was extracted from the data (Results) and the conclusions drawn (Creswell, 1998).

Consent to perform this study was obtained from the Ethics Committee of the Health Sciences Faculty, University of Cape Town. All participants gave informed consent for the interview. It was emphasized that declining to participate in the study would not prejudice further management.

## Results

### *Demographic information*

Women had a mean age of 31.5 years (range 21–41) and a mean duration of infertility of 4.8 years (range 1–15). Eighteen women had no live child and only three participants had a child in the current relationship. None of the women had more than one live child. All but four of the participants were married.

### *Psychological suffering*

All women verbalized intense emotions when talking about their childlessness. 'Burning pain', anger, deep sadness, bitterness, guilt, loneliness and desperation were feelings frequently described. Several informants cried during the interview. Some women referred to episodes of 'burn out' and 'break downs' which they experienced because of childlessness. Two women made reference to suicidal thoughts. One of them said: 'I went out with this guy and I couldn't fall pregnant. Now he went for men, he went to go have sex with men. So it means I am useless . . . That night . . . I wanted to put myself underneath the train.' This woman had experienced the break-up of several relationships because of her inability to conceive.

Women explained that 'wanting a child was their only wish' and in order to see it come true they were prepared to do 'anything'. Answers to the question, why a child was wanted, typically included: 'all women want to have children', 'every man wants to have a child', 'there is no purpose in life, if you can't have children' and wanting to give love to a child.

### *Marital instability*

Many women felt that infertility posed a serious threat to their relationships and were deeply concerned about this. Women feared and experienced this threat in two different ways:

abandonment and/or divorce or infidelity. Most informants appeared defenceless against the threats to their relationship and many considered fertility as a primary function of being a woman. Most women did not seem to question this role and were aware of the consequences if they did not fulfil their 'function'. One informant said: 'I cannot be anybody in the world if I cannot bear children. He will look for another woman who can bear children.' Another explained that 'not getting a child causes bad relations in the family' and some women avoided marriage because of this. The influence of the extended family on the marital relationship was evident in several interviews. This influence was both positive (offering support and guidance) and negative (a source of abuse and additional pressure).

Submission to the consequences of infertility was also reflected in the experience of this woman: 'Then my husband started having children outside our marriage . . . I even went with him to go visit all his children.' A few women thought of breaking off the relationship themselves, but not without anguish: 'I have been lying awake at night thinking what is he going to do? Will he go somewhere else or will he stand by me? . . . I will give him his freedom . . . he can still make a life for himself.' Some of the Muslim women feared that the husband would take a second wife. One informant explained that according to their religion the husband must have the blessing of the first wife before he may take a second wife. But this is not required from a woman who cannot conceive.

Not all women felt threatened in their relationship. Several women described their husband as being supportive and understanding. They trusted their partners and saw them as a friend, often as their only friend. Some women expressed concern and sympathy for their husbands. They felt that they, too, 'missed out a lot'. However, a few women were concerned that a good relationship might change if the problem of infertility persisted. 'Maybe if he can find out for sure that I cannot have babies, he could start treating me badly, but now he is still treating me well.'

Although women seemed to carry the main burden of the social consequences of infertility there was some evidence that the role of men could also be threatened. 'If he can't give me children I can actually do as I please. He is the man and the main figure in the family unit but if he cannot complete it, then he is no longer the main figure', one woman said.

### *Stigmatization and abuse*

For most women infertility had considerable social implications other than affecting their marital relationship. Many women felt stigmatized and ridiculed in their families and in the community. Women described their experiences in many different ways. 'You see, back home in the homelands you don't remove the 'doek' [scarf worn by the bride] until you have a child. If you don't get a child it is better to run away or you will be laughed at', one informant explained. 'It is bad amongst we Xhosa people, because they laugh at you when you cannot get a child.' 'They say . . . why did you marry a thing that cannot get children?'

Many women described how they were sworn at, shouted at, cursed and victimized. Some felt they were an outcast, especially within their husbands' family. 'Idlolo' (barren) and 'stjoekoe' (failure) were words used to scorn an infertile woman. Although some women were able to ignore such verbal abuse, it caused feelings of pain, sadness and anger in many others. 'Stjoekoe, they throw it at me . . . I feel [like] junk. That is why I don't have no friends', one informant explained. A few women were accused of causing their own childlessness. 'Where's all the children . . . every time you are pregnant you drink them away . . . (you) flushed them down the toilet', one woman was told by her mother.

In addition to verbal and emotional abuse a few women spoke about physical abuse. This was always from a male partner and had occurred mostly in a previous relationship. Most women attributed the abuse to their childlessness: 'He started beating me up, it was almost like he was taking out all the grudges because I cannot give him a child.' The difficulty of accessing help and breaking out of this abusive cycle is borne out by the following report: 'He just started slapping me around, beating me. We rented (accommodation) from people, but they would never hear me. When he started beating me, I would never make a sound. I do not want people to know what is happening in my life.'

### *Social pressure*

If not openly blamed, women frequently felt pressurized to get pregnant. Common questions such as 'when are you going to have a baby', although not necessarily intended to hurt, often inflicted pain. One woman claimed that it was almost 'like they [in-laws] were watching my period.' Many women experienced this pressure particularly at family gatherings and felt reminded, both intentionally and unintentionally, of their different status as an infertile woman. 'You know, you almost feel left out of the picture. They all have their kids, they are sending them to school and here you are still sitting without children', one informant explained. Another one was in tears when she said: 'You don't feel like you want to go and visit. Like at the gathering, the moms like to talk about their children . . . Then you sit there and just listen, you can't talk to them. It is times like that when it really hurts you.'

### *Support and secrecy*

Women were not directly asked about their support structures. However, as women related their experiences of involuntary infertility, sources of support and ways of coping became apparent. Several women indicated that they received support from their husbands. But the shared burden of infertility appeared to create barriers for some couples that avoided discussing this topic. A few women received help from the extended family. 'We have support from all the members of the family. Both families. We would go to the family and talk to them and they would give us advice. My mother and his mother, they are the older people and they know more about these things', one informant explained.

Religious belief was an important source of support. This was experienced by all groups of informants and expressed in

similar ways: 'We leave it all to God. God will protect us.' The belief that God will provide did not prevent the women from actively seeking help. 'Our belief is that God gave the doctors the idea of how to go about these things', one informant explained. However, religion was not always a source of support as one woman felt punished by God with infertility for having had premarital sex.

A barrier to support appeared to be the 'secrecy' with which many women handled their childlessness. Few informants felt that they could discuss their 'problem' openly. Many women were cautious and selective when confiding in others. Confidants often shared a similar background. 'My other friend is also having problems conceiving . . . We share that pain together.' For some women this 'bond' with another infertile woman created feelings of both support and jealousy. A woman spoke about the 'competition' to fall pregnant first and how she was praying that her friend 'would not fall pregnant before me.' Later in tears she felt guilty for these thoughts.

Several women did not want to speak at all to others about their involuntary childlessness. Sometimes this wish for secrecy reflected a sense of 'privacy', a feeling that it was 'between me and my husband'. Many other times it was based on fear. 'I am afraid to speak to people about something like that . . . because they are going to tell the whole world that . . . can't fall pregnant.' In order to protect their 'secret' some women would lie: 'I lied to them . . . I told them that with my current husband I don't want to have a child and I want to have my womb removed', one informant told us. Another explained: 'I defend myself . . . if a person is asking me 'ooh, you still have no child' I say 'ooh, what am I going to do with a child', but hey, inside it is painful'.

Finally, one woman tried to cope with the help of drugs. 'I even started drinking . . . to help me forget . . . because men leave me as I cannot have children. You must have your own, even if that child dies later on, they say at least you had one.'

## Discussion

The results of this study indicate considerable personal suffering together with possible serious social consequences among infertile women from a culturally diverse, urban community in South Africa. Our findings are in keeping with other qualitative and quantitative studies which indicate an overwhelmingly negative experience of the inability to conceive (Sabatelli *et al.*, 1988; Wright *et al.*, 1991; Van Balen and Trimbos-Kemper, 1993; Kemmann *et al.*, 1998; Matsubayashi *et al.*, 2001). Loss of self-esteem, anxiety and depression, hopelessness, guilt and marital difficulties are all recognized consequences of infertility. As the desire to have a child has been said to be among the strongest emotions that people experience, it is not surprising that infertility has been considered to be life's worst experience by those who suffer from it (Freeman *et al.*, 1985; Downey and McKinney, 1992; Greil, 1997; Seibel, 1997). Similar to other studies, many infertile clients seemed willing to do 'anything' in order to resolve their involuntary childlessness (Kemmann *et al.*, 1998).

Studies from all parts of the world report a 'normative pressure' to reproduce. According to Sandelowski the—albeit involuntary—violation of the behavioural norm to reproduce results in a 'deviant status' of the infertile (Sandelowski, 1988). This in turn creates feelings of 'not fitting in', 'being different' and 'losing out'. The results of our study are in keeping with this concept. However, when the psychological and social implications of this deviant status are analysed, women in the developing world seem to carry additional negative experiences. Stigmatization, ostracism, marital instability and abuse are not unique findings but they appear to occur more often and with increased severity. This is borne out by a few other studies which have evaluated the social implications of infertility in Africa. Essentially all African cultures see children as the purpose of marriage. Infertility is recognized as a major cause of divorce and abandonment throughout the continent (Leke *et al.*, 1993; Sundby, 1997; Larsen, 2000; Walraven *et al.*, 2001).

A study from Nigeria indicated that infertile women suffer physical and mental abuse, neglect, economic deprivation and social ostracism (Alemnji and Thomas, 1997). Infertile women in Mozambique are excluded from important social events and ceremonies (Gerrits, 1997). Economic deprivation has also been reported from the Gambia where, under some customary laws, childless women have very few rights to inherit property from their husbands (Sundby, 1997). It is of interest to note that similar social consequences have been reported from developing communities in other areas of the world. Infertile women from an urban slum population in Bangladesh have been reported to experience a loss of purpose in life, marital insecurity, stigmatization and abuse (Papreen *et al.*, 2000). Similar to our study these women frequently suffered abuse from the husband's family. The level of abuse was deemed to be high enough to push a woman to suicide. These similarities between different developing communities would indicate that the negative social implications of infertility are probably not the consequence of a specific culture, but secondary to the extremely low social and economic status of women in many parts of the developing world where their prime function is successful reproduction.

For many women the psychological implications and social consequences of involuntary childlessness were compounded by a lack of support. One barrier to support might be the secrecy with which many women handled their problem. As this was often out of fear of negative social repercussions, it has to be assumed that support is truly lacking. In order to avoid the label of infertility, some women pretended that they did not wish to conceive. A similar strategy was found among infertile women living in a slum in Bangladesh, who feigned miscarriages in order to appear fertile (Papreen *et al.*, 2000). Some women received help from other infertile women, but a 'competition to conceive' undermined some of these bonds. The tenuous relationship between infertile women, which might be a reason for their involuntary togetherness and may acquire a hostile component, has been previously described (Sandelowski, 1988). Unwillingness to openly address the

status of infertility may even persist during a consultation with a health service provider, when women may complain about vague pains, vaginal discharge or menstrual irregularities rather than involuntary childlessness (Dyer *et al.*, unpublished data). This 'secrecy' with which many women handle their involuntary childlessness—for reasons of 'privacy' and fear—is likely to contribute to the 'culture of silence' that is said to surround several reproductive health problems in Africa (Walraven *et al.*, 2001).

The effect of infertility on reproductive health in the developing world is beginning to be appreciated and the recommendation has been made that countries, despite poor resources, should develop policies on infertility care (Van Balen and Gerrits, 2001). We fully support this recommendation. As emphasized before, such policies have to consider the socio-cultural context of involuntary childlessness in a given country or community and require cultural sensitivity in the delivery of health services. Our study provides important information in this regard as it highlights the range and depth of experiences associated with involuntary childlessness across this heterogeneous study population. Insight into the range of experiences will contribute to the delivery of a culturally sensitive health care, e.g. by understanding that some women cannot get married without demonstrating fertility, while others may consider infertility a punishment for premarital sex. Understanding the depth of experiences should increase the awareness of health service planners and providers about the potentially serious implications of involuntary childlessness among women from our community. Generally speaking, this awareness is still lacking as national and international attention is focused on the down-regulation of fertility in the developing world (Papreen *et al.*, 2000; Van Balen and Gerrits, 2001).

Our study was conducted on 30 women from a diverse cultural urban community who presented to a tertiary institution for infertility treatment. Although a conscious decision had been taken to exclude men from this study, their influence on women's experiences and on health-seeking practices is recognized and requires further research. Future studies are also indicated to evaluate the experiences and attitudes of infertile couples who are either unwilling or unable to access medical treatment.

We conclude that this qualitative study on 30 infertile women from a South African urban community indicates that for a large number of women involuntary childlessness has serious social consequences. Although care should be taken not to generalize—not all participants were affected—women in our study were exposed to considerable abuse, stigmatization and marital instability. Our results are in keeping with reports from other African countries. The severe social consequences are probably based on a stronger behavioural norm to reproduce when compared with industrialized countries. Closely linked to this is the low social and economic status of women in Africa. For many infertile women in the developing world, these negative experiences form an integral part of involuntary childlessness.

Public health planners need to take note of the psychological and social implications of involuntary childlessness in the

developing world. It is largely through these implications that the seemingly 'benign' condition of infertility seriously affects both women's reproductive and general health. Supportive counselling, delivered in a culturally sensitive way, has to form an integral part of treatment. Ultimately, the underlying issues go far beyond the effective management of infertility and represent a call for the recognition of the reproductive rights of women from developing communities and, more importantly, the improvement of their social and economic status.

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