

**INFERTILITY IN THE PUBLIC HEALTH CARE SYSTEM
IN SOUTH AFRICA: PATIENTS' EXPERIENCES,
REPRODUCTIVE HEALTH KNOWLEDGE AND
TREATMENT-SEEKING BEHAVIOUR**

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Reproductive Medicine, Department of Obstetrics and Gynaecology
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CONTENTS

DECLARATION	xi
ABSTRACT	xii
ACKNOWLEDGEMENTS	xiv
LIST OF TABLES	xvii
LIST OF FIGURES	xix
FOREWORD	xx

CHAPTER 1: INTRODUCTION

1.1. BACKGROUND	1
1.2. LITERATURE REVIEW	3
1.2.1. Preface	3
1.2.2. Prevalence and Biomedical Causes of Infertility	3
1.2.3. Perceived Causes of Infertility	7
1.2.4. The Value of Children	12
1.2.5. Social Consequences of Infertility	15
1.2.6. Health-Seeking Behaviour and Health Care	21
1.2.7. HIV/AIDS and Infertility	25
1.2.8. Social Consequences of Infertility in a Global Perspective	30
1.2.9. The Globalisation of Assisted Reproductive Technologies	33
1.3. AIM AND OUTLINE OF THE DISSERTATION	36

CHAPTER 2: RESEARCH SETTING AND METHODS

2.1. INTRODUCTION	38
2.2. RESEARCH SETTING	38
2.2.1. The Infertility Service	39
2.3. PATIENT RECRUITMENT AND DATA COLLECTION	41
2.4. QUALITATIVE RESEARCH METHODS	42
2.4.1. General Considerations	42
2.4.2. Qualitative Description	44
2.4.3. Validity and Reliability	45
2.5. RESEARCH ETHICS	48
2.6. CONSTRAINTS AND POSSIBLE LIMITATIONS	49

CHAPTER 3: REPRODUCTIVE HEALTH KNOWLEDGE, HEALTH-SEEKING BEHAVIOUR AND EXPERIENCES RELATED TO INVOLUNTARY CHILDLESSNESS AMONG WOMEN SUFFERING FROM COUPLE INFERTILITY

3.1. INTRODUCTION	52
3.2. METHODS	53
3.3. RESULTS	54
3.3.1. Demographic Information	54
3.3.2. Knowledge of Fertility	54
3.3.3. Knowledge of Causes Of Infertility	55
3.3.4. Access to Health Care	56
3.3.5. Traditional Health Care	57
3.3.6. Women's Expectations of the Infertility Service	57
3.3.7. Motivation for Treatment	59
3.3.8. Emotional Reactions to Infertility	59
3.3.9. Effects on the Marital Relationship	60
3.3.10. Stigmatisation and Abuse	61
3.3.11. Social Pressure	62
3.3.12. Support and Secrecy	62
3.4. DISCUSSION	64
3.5. SUMMARY	71

CHAPTER 4: PSYCHOLOGICAL DISTRESS AMONG WOMEN SUFFERING FROM COUPLE INFERTILITY – A QUANTITATIVE ASSESSMENT

4.1. INTRODUCTION	72
4.2. METHODS	74
4.2.1. Statistical Analysis	76
4.3. RESULTS	77
4.3.1. Socio-Demographic Characteristics	77
4.3.2. Psychological Symptom Status	78
4.3.3. Abuse	82
4.3.4. Help-Seeking Process	84
4.3.5. Women's Expectations of the Infertility Service	84
4.3.6. Clinic Access	85
4.4. DISCUSSION	86
4.5. SUMMARY	95

CHAPTER 5: PATIENT SATISFACTION WITH THE DIAGNOSTIC PHASE OF INFERTILITY MANAGEMENT AND REASONS FOR NON-COMPLIANCE

5.1. INTRODUCTION	96
5.2. METHODS	97
5.3. RESULTS	99
5.3.1. Presentation of Findings	99
5.3.2. Rate of Compliance and Demographic Information	99
5.3.3. The First Clinic Visit	100
5.3.4. Experience and Health Care Barriers Related to Further Clinic Visits	101
5.3.5. Reasons for Non-Compliance	104
5.3.6. Suggestions for Improvements	106
5.4. DISCUSSION	106
5.5. SUMMARY	116

CHAPTER 6: REPRODUCTIVE HEALTH KNOWLEDGE, HEALTH-SEEKING BEHAVIOUR AND EXPERIENCES RELATED TO INVOLUNTARY CHILDLESSNESS OF MEN SUFFERING FROM COUPLE INFERTILITY.

6.1. INTRODUCTION	117
6.2. METHODS	118
6.3. RESULTS	119
6.3.1. Demographic Information	119
6.3.2. Knowledge of Fertility	119
6.3.3. Knowledge of Causes of Infertility	120
6.3.4. Expectations and Concepts of Biomedical Infertility Management	121
6.3.5. Treatment-Seeking Behaviour	122
6.3.6. The Wish for a Child	124
6.3.7. Experiences of Infertility	125
6.3.8. Effects on the Marital Relationship	125
6.3.9. Experiences in the Family Setting	126
6.3.10. Experiences in the Community	127
6.4. DISCUSSION	129
6.5. SUMMARY	138

**CHAPTER 7: PSYCHOLOGICAL DISTRESS AMONG MEN SUFFERING FROM
COUPLE INFERTILITY - A QUANTITATIVE ASSESSMENT.**

7.1. INTRODUCTION	139
7.2. METHODS	140
7.2.1. Statistical Analysis	141
7.3. RESULTS	142
7.3.1. Socio-Demographic Characteristics	142
7.3.2. Psychological Symptoms Status	144
7.3.3. Historical Comparison of the Male and Female Data	145
7.4. DISCUSSION	148
7.5. SUMMARY	157

CHAPTER 8: MOTIVATIONS FOR PARENTHOOD – A PILOT STUDY

8.1. INTRODUCTION	158
8.2. METHODS	160
8.2.1. Statistical Analysis	163
8.3. RESULTS	165
8.3.1. Socio-Demographic Characteristics	165
8.3.2. Parenthood Motives	166
8.3.3. Reflection, Strength of Desire and Consensus Between Partners	169
8.3.4. Parenthood Motives and Strength of Desire	170
8.4. DISCUSSION	171
8.5. SUMMARY	179

CHAPTER 9: HIV-NEGATIVE INFERTILE COUPLES: THEIR KNOWLEDGE OF HIV/AIDS AND THEIR ATTITUDES TOWARDS REPRODUCTION IN HIV-POSITIVE COUPLES.

9.1. INTRODUCTION	180
9.2. PATIENTS AND METHODS	182
9.2.1. Statistical Analysis	183
9.3. RESULTS	184
9.3.1. Knowledge of HIV/AIDS	184
9.3.2. Attitudes Towards Fertility and Infertility Treatment in HIV Infected Couples	185
9.3.3. Perceived Risks of HIV/AIDS in Pregnancy	187
9.3.4. Association Between Parenthood Motives and Attitudes Towards Fertility and Infertility Treatment	189
9.4. DISCUSSION	190
9.5. SUMMARY	196

CHAPTER 10: “I AM STILL HOPING, BECAUSE I AM STILL ALIVE” – EXPERIENCES AND PERSPECTIVES OF HIV-POSITIVE, INFERTILE MEN AND WOMEN.

10.1. INTRODUCTION	197
10.2. METHODS	198
10.3. RESULTS	199
10.3.1. Recruitment	199
10.3.2. Demographic Information	200
10.3.3. Experiences Related to Infertility	202
10.3.4. The HIV Test	202
10.3.5. General Health Status	204
10.3.6. Experiences in the Relationship	204
10.3.7. Living With HIV	207
10.3.8. The Wish for a Child	208
10.3.9. Perceived Risks Of HIV Infection in Pregnancy	211
10.3.10. Attitudes to Infertility Management	213
10.4. DISCUSSION	214
10.5. SUMMARY	224

CHAPTER 11: CONCLUSIONS AND RECOMMENDATIONS

11.1. CONCLUSIONS	225
11.2. RECOMMENDATIONS	227
11.2.1. Recommendations for Health Service Delivery	227
11.2.2. Recommendations for Future Research	228

REFERENCES	231
PUBLICATIONS AND PRESENTATIONS	253
APPENDICES	256
APPENDIX A – INTERVIEW GUIDE (CHAPTERS 3 AND 6)	256
APPENDIX B – STUDY QUESTIONNAIRE (CHAPTERS 4 AND 7)	257
APPENDIX C – INTERVIEW GUIDE (CHAPTER 5)	266
APPENDIX D – STUDY QUESTIONNAIRE (CHAPTERS 8 AND 9)	267
APPENDIX E – INTERVIEW GUIDE (CHAPTER 10)	271
APPENDIX F – STATISTICAL ANALYSIS (CHAPTER 8)	272

DECLARATION

I, Silke J Dyer, hereby declare that this thesis is my own work, both in concept and execution, but for the normal guidance received from my supervisor and contributions from others as outlined in the acknowledgments. Neither the substance nor any part of this thesis has been, is being or is to be submitted for another degree at this University or at any other university.

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Date

ABSTRACT

Infertility is a common reproductive health problem in Africa. The experiences of men and women who are unable to conceive, their constructs of infertility, their motives for parenthood, and their health-seeking behaviour are, however, inadequately documented in South Africa. In order to improve our understanding of the patients' perspective of infertility, seven studies were conducted employing both qualitative and quantitative research methodology. Study participants were recruited from the infertility clinic at Groote Schuur Hospital, Cape Town, a tertiary referral centre within the public health care system.

The central themes explored in the qualitative studies included reproductive health knowledge, health-seeking behaviour, barriers to health care, experiences related to involuntary childlessness, and the reality of infertility and HIV infection. Data from both men and women were collected through in-depth interviews, and the results were analysed according to the principles of descriptive analysis. In the quantitative studies psychological distress was measured and motives for parenthood were assessed with the use of two standardised instruments (the Symptom Checklist-90-R for the measurement of acute psychological symptom status and the parenthood-motivation list). In addition, participants' attitudes towards reproduction in HIV-infected individuals were evaluated. Standard statistical methods were used to analyse quantitative data.

The results of these studies demonstrated that men and women had limited knowledge about fertility, infertility, and biomedical infertility management. Some men and women held traditional beliefs and had accessed traditional healers. Most informants appeared highly motivated to engage in biomedical infertility management. Treatment satisfaction varied and reasons for non-compliance were both service and patient-related.

Infertile couples gave many reasons for wanting a child and expressed a strong desire for parenthood. For many men and women the inability to conceive was associated with

negative emotions, marital instability, abuse, stigmatisation, and loss of social status. Psychological distress levels were significantly higher in infertile women when compared to women using contraception, and in infertile men when compared to fertile men. Infertile women who reported intimate partner abuse were particularly distressed.

The diagnosis of HIV infection did not eliminate the wish for a child in infertile couples, and in the absence of medical assistance many continued to attempt conception. The concomitant experience of infertility and HIV infection was associated with considerable suffering. The majority of HIV-negative, infertile men and women opposed reproduction in HIV-positive couples.

Collectively, the results of these studies provide new insights into the manner in which men and women who access the public health system in South Africa construct, experience, and respond to infertility. Understanding these details of the patients' perspective should improve the management of infertility in this patient population.

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LIST OF TABLES

CHAPTER 4

Table 4.1. Socio-demographic characteristics of study group and control group	78
Table 4.2. Mean T scores among study group and control group	79
Table 4.3. SCL-90-R items resulting in potentially confounding interpretations	81
Table 4.4. Comparison between original mean T scores and revised mean T scores among study group and control group	82
Table 4.5. Mean T scores among infertile women in abusive and non-abusive relationships	83
Table 4.6. Time period spent on help-seeking process and sources accessed for help prior to referral	84
Table 4.7. Expected nature, duration, and success of infertility treatment	85

CHAPTER 5

Table 5.1. Reasons for non-compliance with the initial phase of infertility management	105

CHAPTER 7

Table 7.1. Socio-demographic characteristics of study group and control group	143
Table 7.2. Mean T scores among study group and control group	144
Table 7.3. Socio-demographic characteristics of male and female study group and male and female control group	146
Table 7.4. Mean T scores among infertile men and infertile women	147
Table 7.5. Mean T scores among fertile men and women currently using contraception	148

CHAPTER 8

Table 8.1. Parenthood-motivation list	162
Table 8.2. Socio-demographic characteristics	166
Table 8.3. The presence of parenthood motives among study participants	167
Table 8.4. Responses to the individual items of the parenthood-motivation list	168
Table 8.5. The association between parenthood motives and strength of desire for a child	171

CHAPTER 9

Table 9.1. Attitudes to spontaneous and treatment induced fertility in HIV-positive couples	185
Table 9.2. Perceptions of HIV/AIDS-related risks in pregnancy	188

CHAPTER 10

Table 10.1. HIV status, relationship status, and the wish for a child among informants	201

APPENDIX F

Table F.1. Responses of women to the 18 items of the parenthood-motivation list	273
Table F.2. Responses of men to the 18 items of the parenthood-motivation list	274
Table F.3. Details of the latent trait analysis of the triplet coding for well-being	275
Table F.4. Chi-square statistics of the observed and expected differences in the response pattern to the six triplets according to latent trait modelling	275
Table F.5. Factor loadings and communalities with varimax rotation (female respondents)	276
Table F.6. Factor loadings and communalities with varimax rotation (male respondents)	277

LIST OF FIGURES

CHAPTER 8

Figure 8.1. Time spent thinking about reasons for wanting a child 169

Figure 8.2. Informants' assessment of own strength of desire when compared to that of their partner 170

FOREWORD

The research for this dissertation originated from clinical audit. I was tasked with the delivery of the infertility service at Groote Schuur Hospital as a junior consultant towards the end of 1993. Following a period of skills acquisition and consolidation, I initiated a number of clinical audits. Apart from assessing pregnancy rates following various treatment modalities, I was interested in the overall profile of couples who entered our service - what were the leading causes of infertility, how many couples were treated successfully and how many remained childless? Audit demonstrated that these parameters were impossible to establish due to a high rate of non-compliance both during the early phase of the investigations as well as at various stages of clinical interventions. It was my impression at the time that this high drop-out rate was not in keeping with patients' desires for a child, and I started to speculate on the causes of non-compliance.

The idea to investigate rather than speculate came from my supervisor Professor Zephne M van der Spuy. I thus embarked on the first study which underpins this dissertation utilising qualitative research methods in order to gain insight into women's expectations of a tertiary level infertility service. The study generated findings not only about expectations but also about experiences secondary to involuntary childlessness, and the latter drew attention to the fact that we knew very little about the psychological and social context of involuntary childlessness in our community. The results of this study gave rise to new research questions which were explored and which in turn led to further studies.

The initial research preceded the intention to write a dissertation. Some of the studies presented in this dissertation have already been published in an international peer-reviewed journal, but all of the data have been re-worked and expanded to form a coherent, single text. It is possible that had the research been planned as a PhD project from the beginning, it may have followed a more rigid planning schedule. The relative absence of such a schedule was, however, also a strength of this work as

it facilitated a research structure in which each study was built upon the findings of the preceding study. The central research question that was followed throughout all of the research was “How do men and women from our communities experience, construct, and respond to infertility?” This research question was based on the awareness that the delivery of appropriate health care, especially in our cross-cultural setting, required not only an understanding of the medical aspects of infertility but also insight into the psychosocial context of involuntary childlessness.

The research question brings these studies into close proximity with the social sciences. The application of research methods (qualitative research using in-depth interviews), which are more frequently used by the social than the health scientist, further affirms this proximity. Although I believe that a narrowing of the gap between social sciences and health sciences is desirable, I have to state very clearly that this dissertation presents studies in health sciences and not in social science and that it is written in my capacity as an obstetrician gynaecologist with the desire to improve patient care. My original contribution to the field of health sciences is the description of a social context of infertility in an urban South African community. The need for this contribution is recognised in the mission statement of our Faculty, which highlights the importance of “promoting understanding of the social context of disease and health” (Faculty of Health Sciences of the University of Cape Town, 1994). Although I do not claim that the findings presented in this dissertation can be extrapolated to all infertile men and women in South Africa or indeed Africa, I do believe that this research sensitises other health care workers to the nature of involuntary childlessness in our region and that new insights for the delivery of infertility-related health care can be derived from this work.

CHAPTER I

INTRODUCTION

1.1. BACKGROUND

Africa is a markedly pro-natalist continent. Marriage is almost universal and occurs at an early age. A leading purpose of marriage is to have children and voluntary childlessness is rare. High total fertility rates paralleled by falling mortality rates translated into a steep population growth curve in most countries in the last few decades. Many African governments tried to reduce population growth, and international health care policies and funding have focused on population regulation in recent years (Leonard, 2002; Hollos, 2003; Inhorn and Buss, 1994).

The global concern over Africa's population growth has frequently obscured a second and somewhat paradoxical fertility problem, namely that of infertility (Bergstrom, 1992; Bamba, 1999; Orji et al., 2002; Hollos, 2003; Inhorn 2003b). Africa has a high prevalence of infertility, which is largely based on a high prevalence of sexually transmitted diseases (STDs) and pregnancy-related sepsis in a setting of poor general health and inadequate health care (Schrijvers et al., 1991a; Sciarra, 1993a; Sciarra, 1997; Okonofua, 1999). Pregnancy complications and STDs are in turn fuelled by the desire to have children. The need for greater recognition of the magnitude of the problem of infertility in Africa has been acknowledged, and appropriate health care policies are now required (Okonofua, 1999; van Balen and Gerrits, 2001; Geelhoed et al., 2002).

Infertility is usually defined, in medical terms, as the failure to conceive after 12 months of regular, unprotected intercourse. According to this definition, infertility is said to affect 8 – 14 % of couples of reproductive age in developed countries (World Health

Organization, 1991; Sciarra, 1997). The advances in reproductive technologies have revolutionised infertility management and a significant number of live births can now be attributed to these technologies in the Western industrialised world (van Balen, 2001; Society for Assisted Reproductive Technology and the American Society for Reproductive Medicine, 2004; Andersen et al., 2005). These biomedical developments have been paralleled by a growing awareness that infertility is not only a physiological or patho-physiological condition but also a socially constructed reality (Berg et al., 1991; Greil, 1997; Sandelowski, 1999). Understanding the reality of infertility has in turn influenced the medical approach to infertility to the effect that counselling has become a central, and in some countries such as the UK and Australia, even a mandatory part of assisted conception (Klock and Maier, 1991; Seibel, 1997; Boivin and Kentenich, 2002).

No such revolution has taken place in Africa. Infertility remains a common reproductive health problem affecting as many as 20 –30% of couples in some areas (Frank, 1983; Ericksen and Brunette, 1996; Larsen, 2000). The majority of these patients do not have access to affordable or effective infertility management (Gerrits, 1997; Walraven et al., 2001; Leonard, 2002). If appropriate treatment can be accessed it is usually delivered by health care workers who are trained in Western biomedicine and who may not fully appreciate the lived experience of infertility in the local communities (Inhorn and Buss, 1994). This may limit their ability to counsel their patients and to provide patient-centred care.

What evidence can be derived from the literature pertaining to the construct and social context of infertility in Africa is presented in the following section.

1.2. LITERATURE REVIEW

1.2.1. Preface

A central question motivated the research program from which this dissertation emanated: how do men and women experience, construct, and respond to infertility in our community? In this chapter the peer-reviewed literature pertaining to this question is reviewed. Epidemiological data are integrated to outline the magnitude of the problem of infertility and to describe the underlying causes. The review focuses on publications from Africa, and some comparisons are made with reports from other developing countries as well as the industrialised world.

English-language publications were identified through a MEDLINE search. The basic key words were 'infertility', 'reproductive health', 'psychology', 'psychosocial factors', 'Africa' and 'developing world'. The bibliographies of the identified publications were further searched for references. The Cochrane reproductive health library was also accessed for information, but no studies in the area of interest could be identified.

The terms 'infertility' and 'inability to conceive' are used synonymously in this review. Although the term 'involuntary childlessness' is also commonly used as a 'loose' synonym for infertility, it will be used here in its correct meaning which includes the inability to conceive, pregnancy wastage, and infant loss (Belsey, 1976).

1.2.2. Prevalence and Biomedical Causes of Infertility

❖ Prevalence Rates and Epidemiological Risk Factors

Ideally, any study aimed at establishing the prevalence rate of infertility in a given region should be based on medical records and evaluations. Not surprisingly, in Africa such data are seldom available for any representative national or cross-national population groups. In the absence of such data the prevalence of infertility has been estimated through birth records from demographic surveys.

Deducing infertility prevalence from birth histories rather than clinical records is associated with a shift in the definition of infertility as “the failure to conceive after one year of regular unprotected intercourse” to defining infertility as “the failure of non-contracepting sexually active women or couples to have a live birth over a certain period of time” (Larsen and Menken, 1989). This period needs to be longer than the one year period used in the clinical definition in order to minimize, for example, the impact of temporary sexual abstinence or post-partum sub-fecundity. Based on population studies and mathematical models, non-conception over five to seven years of sexual exposure appears to yield adequate estimators of infertility prevalence (Larsen and Menken, 1989; Larsen, 1994). This demographic approach does not allow us to distinguish between non-conception and pregnancy loss, and calculated figures may therefore not be reliable markers of infertility according to the biomedical definition. They do, however, outline the magnitude of the problem of involuntary childlessness in Africa.

Ericksen and Brunette (1996) utilised this approach in their analysis of cross-national patterns and predictors of infertility among 27 African nations which did not include South Africa. Birth histories were derived from national demographic and health surveys as well as world fertility surveys. The data are comparable as the surveys share the same methodology and data processing. The authors calculated infertility rates among sexually experienced women aged 20 to 41 years who had not given birth after exposure to conception for five to seven years.

Infertility rates based on 5 years of sexual exposure ranged from 8.6% (Burundi) to 17.1% (Lesotho) while the comparative ranges for 7 of non-conception were 11.5% (Burundi) to 22.4% (Zimbabwe) respectively. Southern Africa (Namibia, Botswana, Zimbabwe and Lesotho) reported prevalence rates in the highest quartile (average 19.1%) which the authors attributed to high rates of sexually transmitted diseases. Recognised limitations of the study included recall errors of birth and marriage dates in regions in which literacy rates are low and where calendars may play a limited role in marking life events. In addition, women who claimed non-biological children as their own may have been incorrectly assessed as ‘fertile’.

An update of these data based on more recent population surveys and the inclusion of four additional countries (Central African Republic, Comoros, Mozambique and Nigeria) was provided by Larsen (2000). The author analysed birth histories of ever-married women aged 20-44 years and defined primary infertility as childlessness after 7 years following first marriage and secondary infertility as the absence of a live birth 5 years after the delivery of the last child. The data do not allow a distinction between voluntary and involuntary childlessness but contain information on the use of contraceptive methods.

In order to allow for the influence of contraceptive use, Larsen calculated a lower and upper estimate of infertility. The lower estimate was underpinned by the hypothesis that all current users of contraceptive methods were fertile. The upper estimate was based on the assumption that no woman used contraception and that there was no voluntary childlessness. According to these definitions the prevalence rate of primary infertility was low in all countries in the survey and did not exceed 6%. In contrast, prevalence rates of secondary infertility were considerably higher, ranging from 5% (Togo; lower estimate) to 26% (Central African Republic; upper estimate). These results are in keeping with the previous study by Ericksen and Brunette (1996). Further break-down by age demonstrated that between 17 % (Togo; lower estimate) and 52% (Mauritania; upper estimate) of women aged 35-39 suffered from secondary infertility. Larsen concluded that infertility constituted a public health problem in sub-Saharan Africa (Larsen, 2000).

Insight into global rates of infertility can be derived from data tabulated by the Division of Family Health of the World Health Organisation (WHO, 1991). In this study infertility was defined as non-conception despite cohabitation and exposure to pregnancy for a period of two years. Information was obtained from varying sources which compromised the ability to compare data. Taking this limitation into consideration the prevalence rate of infertility among women aged 15-49 years ranged from about 5% to 13% in four of the five WHO regions (America, Europe, East Mediterranean Region and South East Asia). In contrast, corresponding rates in Africa ranged between 20% and 40% and reached up to 60% in individual reports. These rates from Africa are higher than in the studies by

Ericksen and Brunette (1996) and Larsen (2000). This discrepancy may be attributed to the fact that in the current study infertility was based on a two year period of non-conception, whilst the other studies derived their figures from five and seven years of non-conception.

Collectively these studies indicate that infertility is a common reproductive health problem in Africa and that prevalence rates are higher than in other parts of the world.

❖ *Biomedical Causes of Infertility*

Comprehensive data on the world-wide causes and patterns of infertility were compiled by the WHO Task Force on the Diagnosis and Treatment of Infertility in a multi-centre study between 1979 and 1984 (Cates et al., 1985; WHO, 1987). Thirty-three medical sites in 25 countries throughout the industrialised and the developing world participated including four sites in Africa (Ibadan, Nigeria; Lusaka, Zambia; Nairobi, Kenya, and Yaounde, Cameroon). Nearly 8500 infertile couples seeking medical evaluation were enrolled, and all sites used a systematic diagnostic approach ensuring comparability of data. Pertinent to this review were the findings that, globally, Africa had the highest rates of secondary infertility and of infection-related childlessness. Acquired tubal pathology and/or pelvic adhesions attributable to infection were demonstrated in 85% of African women when compared to 36% of women investigated in developed countries and 39% of female participants from Asia.

Several studies from single African centres have reported on the causes of infertility, although differences in patient selection and diagnostic evaluations limit the ability to compare results and to extrapolate findings to larger population groups (Cates et al., 1985). Data from our own local community were compiled by Wiswedel and Allen (1989) who evaluated 904 couples attending the Groote Schuur Hospital infertility clinic. The leading causes of infertility were tubal factor infertility (diagnosed in 57% of couples), male factor infertility (36%), and anovulation (29%).

In a study from Durban, South Africa, 100 couples suffering from infertility were investigated at a large tertiary hospital serving a socially disadvantaged, predominantly black population (Chigumadzi et al., 1998). Tubal infertility was diagnosed in 77 couples, 21 men were found to have a male factor, and 18 women were anovulatory. The rate of combined causes of infertility was not stated.

Studies from Kenya, Gabon, Ghana, Nigeria and Tanzania reported tubal pathology in 23% to 83% of infertile couples and a rate of male factor infertility ranging from 8.8% to 45% (Mathews et al., 1981; Collet et al., 1988; Benucci and Resti, 1989; Fiander, 1990; Ikechebelu et al., 2003; Larsen et al., 2005). These studies are difficult to compare as the diagnostic approach is not always specified or differs between studies.

These findings are in keeping with the WHO study and indicate a high prevalence of tubal factor infertility (Cates et al., 1985). Tubal factor infertility and, to a lesser degree, male factor infertility are evidently linked to the high prevalence of sexually transmitted diseases (STDs) as well as to pregnancy-related infections (Belsey, 1976; Muir and Belsey, 1980; Mbizvo et al., 1989; Sciarra, 1997; Folkvord et al., 2005). Although both pregnancy-related sepsis and STDs represent a global health problem, developing countries, especially African countries, are disproportionately affected (Sciarra, 1997; Gerbase and Mertens, 1998;). There are many reasons for this, including poor general health, inadequate and inaccessible health care facilities, unsafe abortion practices, lack of preventative health measures and of effective infection control efforts, as well as sexual behavioural risk factors (Bergstrom, 1990; Ericksen and Brunette, 1996; Sciarra, 1997; Boonstra et al., 2003). The latter are in turn influenced by cultural traditions (early sexual initiation, polygamy, female genital cutting) and socio-political situations in which political unrest, poverty and male labour migration promote non-marital and commercial sex (Bambra, 1999).

1.2.3. Perceived Causes of Infertility

Men and women suffering from infertility seek to explain their inability to conceive. In many non-Western countries individual concepts of health and disease may differ from

the biomedical health model, which underlies modern medical care in both the industrialised and the developing world (Atkinson and Farias, 1995). It is important for health care workers to be aware of their patients' health knowledge and of possible differences between biomedical and lay concepts as these may influence health-seeking behaviour.

While no South African study was identified within the health sciences domain which evaluated knowledge and constructs of fertility and infertility among infertile couples, a few ethnographic and anthropological studies from other African countries offer valuable insights. In a study of the socio-cultural aspects of infertility in Mozambique, Gerrits (1997) conducted in-depth interviews with infertile women from the Macua tribe, a matrilineal ethnic group. Women attributed their childlessness to both traditional and biomedical explanations although the former were mentioned more frequently.

Gerrits divided the traditional explanations into perceived personalistic (or human) causes and naturalistic causes. This dual model of disease causation has been described in other African anthropological studies (Janzen, 1981). Human causes are commonly attributed to inter-personal conflicts which, through the involvement of witchcraft, can generate disease. Natural causes of disease include a wide range of events not attributed to witchcraft.

In keeping with this model, Macua women attributed infertility to the possession by and sexual contact with spirits, as well as witchcraft (Gerrits, 1997). Some of the cultural rites and traditions appeared to make women vulnerable to witchcraft. The initiation rites conducted on young women after menarche involve removal and burial of the pubic hair, and if this is dug up and tampered with by a witch, it is believed that infertility may result. Similarly, the purposeful incorrect burial of the umbilical cord by a birth assistant is believed to cause sterility in the parturient.

A common naturalistic explanation of childlessness was blood incompatibility between partners, especially if the male blood was 'too hot' or 'poisonous' causing dyspareunia

and dysmenorrhoea as well as infertility. The belief that 'norro' (the local term for gonorrhoea) destroyed a woman's womb demonstrates the frequently encountered 'grey area' between traditional and modern explanations. Other biomedical causes mentioned by the informants included sperm problems, retroversion of the uterus, and infections of the ovary.

Sundby (1997) evaluated concepts of infertility among women in the Gambia. Childlessness was often interpreted as being God's will, although witchcraft initiated by evil spirits or jealous co-wives was also a common concern. Other infertility explanations included an unclean womb, weak sperm, and male impotence. The frequency with which these causes were mentioned varied considerably between various ethnic groups in the region.

The Sara are a conflation of several minor ethnic groups in the Chad sharing a common cultural heritage and similar languages. Leonard (2002) conducted an epidemiological and ethnographic study aimed at evaluating the interpretation and experience of childlessness. Data were collected through extensive fieldwork involving household surveys and in-depth interviews with selected infertile men and women. According to this study, Sara people believe that women are born with an unknown number of children located within their bodies (stomach or lower back). At the time of marriage all women are assumed to have children within them and to be able to give birth while it is understood that some may give birth to more children than others.

Couple infertility is usually attributed to the woman unless the man is impotent. A few women are believed to be infertile, because they do not have children inside them and there is no cure for their condition. More commonly, infertility may be explained by the incompatibility of blood between husband and wife, the remedy for which is to take a different partner. Familial discord is another important cause of infertility as family members can issue curses on young girls and women involved in a conflict. Provided reconciliation can be achieved, infertility is not permanent. In addition, numerous other threats to female fertility are believed to exist. These include, among others, early sexual

debut, multiple sexual partners, use of modern contraception, induced abortions, worm infestation, vaginal discharge, and sexually transmitted diseases. Some of these latter complaints show links to the biomedical causes of infertility and women may seek help for these conditions from the modern health sector.

Koster-Oyekan (1999) conducted an anthropological study on perceived causes and treatment of infertility among Yoruba women, who are members of a large ethnic group in Nigeria. Similar to the Sara, the Yoruba believe that women are born with a certain number of children within them, and men are fertile unless impotent. The absent concept of male factor infertility is exemplified in the words of one female informant who said: "Even if he had married ten wives who could not conceive, people would still say that it was his destiny to always marry an infertile woman".

No Yoruba woman is born without reproductive potential. There are natural and spiritual causes of infertility which, once identified, are amenable to treatment. Evil spirits, angered ancestors, and spells cast by spiritualists on behalf of ill-meaning people are spiritual causes of infertility. In contrast, induced abortions belong to the group of natural causes due to the possible damage to the womb or because the woman may have aborted the only child(ren) she was meant to have. All women are believed to have a uterine fibroid which is necessary for conception but which can prevent conception if it grows too big. A less common but interesting concept is that a worm lives in the womb of every woman. Despite sharp teeth this worm is usually harmless and plays with the foetus. At times, however, this worm can turn evil and prevent conception or cause a miscarriage with its teeth. Other explanations include sexual promiscuity and gonorrhoea (which heats the womb and damages the sperm) as well as modern contraception (Koster-Oyekan, 1999).

In an earlier study from Nigeria, Okonofua et al. (1997) conducted focus group discussions with key informants from rural and urban communities in order to ascertain the social context of infertility. The authors reported that in Southwest Nigeria infertility is commonly attributed to abortion, promiscuity, and contraception all of which could

result in the ‘allotted’ number of children being ‘used up’ prematurely. These results are in keeping with the findings reported by Koster-Oyekan (1999), as is the observation that men are generally deemed to be fertile, unless impotent.

Theft and witchcraft are considered prominent causes of infertility by the Bangangte women in Cameroon who believe that fetuses can be stolen from the womb, destroyed before their birth, or prevented from being born (Feldman-Savelsberg, 1994). This destruction of a pregnancy is caused by ‘vampires’ who are usually envious women. Witchcraft can prevent conception by blocking tubes through various fetishes or medicines. Infertility may also be the consequence of a non-arranged marriage, infidelity, or angered ancestors. In addition, a woman’s fertility is perceived to be dependent on the well-being of the divine king.

The persistence of traditional beliefs, despite migration into a different socio-cultural environment, was demonstrated by Yebei (2000) who studied the needs, beliefs and treatment-seeking behaviour of infertile Ghanaian women resident in the Netherlands. Several of the informants considered predestination (God’s will), witchcraft, and family conflict as possible causes of their childlessness. These considerations co-existed with an understanding of biomedical causes of infertility.

In a quantitative study from rural Ghana, Geelhoed et al. (2002) assessed knowledge of the causes of infertility among approximately 2200 men and women of reproductive age. Over half of the informants had no knowledge of any possible cause, and the remaining participants had mostly incomplete knowledge. The commonest biomedical cause mentioned by men was sperm abnormalities (13.3%), while women quoted induced abortion as the leading cause (32.2%). The latter may, according to the authors, reflect the restrictive abortion law in Ghana resulting in unsafe abortion practices. Arguably the most concerning finding of this study was the fact that less than 2% of the study cohort referred to sexually transmitted diseases as a cause of infertility. Similar findings have been reported in a study from Kenya which demonstrated that the knowledge of

biomedical causes of infertility and especially of the role of sexually transmitted diseases was poor in the community (Sekkade-Kigonde et al., 2004).

All these studies demonstrate that many African societies have a multifaceted construct of infertility, which involves biomedical concepts as well as spiritual and cultural dimensions. Some medical anthropologists have, however, viewed the divide between 'modern' and 'traditional' medicine as simplistic as it does not pay tribute to the complex relationship between biomedical concepts of disease and African systems of health and healing (Comaroff, 1981; Janzen and Prins, 1981).

1.2.4. The Value of Children

The literature on the value of children is both extensive and complex and falls predominantly within the domain of the social sciences (Veevers, 1973; Wikman et al., 1992). The main body of this literature stems from the industrialised world, and although a comprehensive review is beyond the scope of this dissertation, a few pertinent issues will be reviewed.

Notwithstanding a considerable increase in voluntary childlessness in the Western industrialised world, parenthood represents a central life goal in most societies (Becker and Nachtigall, 1994; Edelman et al., 1994; Daniluk, 1997). According to Hoffman and Hoffman (1973) the value of children is derived from the functions they serve and the needs they fulfil for both parents and society. Successful procreation is therefore usually valued both at a personal and a socio-cultural level. In addition, there is commonly a religious mandate to reproduce (Veevers, 1973; Serour et al., 1991; Mahlstedt, 1994; Daniluk, 1997).

Although the wish for a child is therefore (almost) universal, the underlying motives for parenthood may be varied. There is no single scientific answer to the question of what motivates men and women to have children. Parenthood motives are complex, often elusive, operate at different levels of consciousness, vary in importance and intensity, may be ambivalent and contradictory, change over time, and are influenced by a large

number of variables (Hoffman and Hoffman, 1973). These authors stated that “the task is to document them [parenthood motives], to sort them into meaningful conceptual schemes, and to study their interactions with other variables”

Not surprisingly a number of different theories, concepts, and approaches have been utilised in the study of parenthood motives (Veevers, 1973; Miller, 1994; van Balen and Trimbo-Kemper, 1995; Wikman and Lalos, 1995; Langdridge et al., 2000). One common approach is to evaluate the positive and negative aspects of children in a cost-benefit model. In this model possible benefits include, among others, emotional rewards, self-fulfilment, marital fulfilment, religious benefits, security in old age, continuity of the family name, gender identity, and social status. In contrast, restriction of freedom, loss of self-actualisation, financial costs, physical demands, and ecological concerns are perceived potential costs of parenthood (Hoffman and Hoffman, 1979; Callan, 1982; Bell et al., 1985; Ramu and Tavuchis, 1986).

Other models include the biological approach which explores parenthood as human instinct or nature, a feminist model which attributes motherhood to patriarchal norms, and a large number of social studies on parenthood which incorporate themes such as religion, civic responsibility, sex and gender identity, emotional needs (such as those related to love and nurturing), and the role of marriage (Veevers, 1973; Newton et al., 1992; Miller, 1994). Many of these studies are complex as they aim to contribute to the understanding of the essence of human reproductive behaviour.

Only one study from an African country could be identified which explored the motives for parenthood in a systematic way. Following a series of focus-group discussions in Southwest Nigeria, Okonofua et al. (1997) reported that the reasons why people wanted to have children could be grouped into five major categories. These included continuation of the family lineage, assistance with work and domestic tasks, joy and companionship, old age security, to obey a religious command to reproduce, and social status. Although the latter reason was deemed important for both men and women, it was considered to be particularly important for women.

Additional insight into the value of children in African communities can be gained from a number of qualitative studies on fertility and infertility, although these studies did not explore parenthood motives *per se*. Interviews with infertile Macua women in Mozambique demonstrated that children are important for the continuation of the family line, for burying and mourning their dead parents, and for social support and security as they contribute to domestic and agricultural tasks and offer care in case of sickness and old age (Gerrits, 1997). Shona women in Zimbabwe define themselves predominantly through marriage and childbearing (Runganga et al., 2001). Children are valued both as an economic asset and a resource, and fertility bestows adult status, social status, and gender identity. In addition, children provide emotional security which women may not experience in their relationship with their partner because of disempowerment. The central role that children play in African communities is evident in many other studies. According to reports from the Gambia, Nigeria, Ethiopia and Ghana, children are valued for reasons of inheritance and continuity, social security and status, and for providing a proper burial for their parents (Sundby, 1997; Koster-Oyekan, 1999; Pearce, 1999; Tilson and Larsen, 2000; Yebei, 2000).

Among the Sara in the Chad, children are believed to be the re-incarnation of ancestors (Leonard, 2002). As ancestors have an important influence on the physical and spiritual well-being of the family, female fertility is seen to reflect a family's standing with the ancestors. In addition, children are central to a woman's social status and gender identity. The role of children as a link to the ancestors is also evident in the Bangangte culture (Cameroon) where the deceased can only become ancestors if they have surviving, well-socialised descendents (Feldman-Savelsberg, 1994). Bangangte children are also a protection against poverty as they strengthen the marriage (divorce is often associated with female poverty), help their mothers cultivate the land, and are a source of support in old age. The mothers of children are considered to be blessed by good fortune and to be competent women.

Women in the Ijaw society (Nigeria) rely similarly on children for social status and security, and for getting help with subsistence-related activities (Hollos, 2003). Fertility is

a prerequisite for attaining full adult womanhood since, traditionally, this requires clitoridectomy which is normally performed in the seventh month of pregnancy. Children, especially boys, play an important role in the lives of their fathers as the power and prestige of the lineage depends on the number of grown-up sons, and land claims are based on the number of a man's children.

In summary, these studies demonstrate that in Africa children play many important roles in the lives of their parents as they secure conjugal ties, confer social status and rights of property and inheritance, assist with labour, offer social security in old age, and provide continuity through re-incarnation and maintaining the family name. At a demographic level the many social and economical benefits of children in a setting where the cost of child-rearing is low will continue to drive high fertility rates (Callan, 1982; Packard and Epstein, 1991). It must be noted in this context that in most traditional societies the net flow of wealth - that is material and non-material goods - is from children to parent. High fertility is therefore a socially and economically sound response to the circumstances of these societies and not, as sometimes argued, the result of ignorance and lack of "family planning" (Caldwell, 1976; Caldwell, 1981).

In contrast, in industrialised countries the flow of wealth goes from parent to child and limiting family size therefore results in socio-economical benefits (Caldwell, 1976). The demographic transition to smaller families requires not only access to contraceptive methods but profound socio-cultural changes in which the value of children and the meaning of parenthood play a central role.

1.2.5. Social Consequences of Infertility

The social consequences of infertility are closely linked to the value and the role of children in a given society. The more central children are to the well-being and functioning of a community, the more significant the consequences of childlessness may be. Many of the studies undertaken in Africa bear testimony to the considerable psychological and social suffering associated with the inability to conceive, particularly among women.

❖ *Stigmatisation and Loss of Social Status*

A common consequence of infertility is stigmatisation and loss of social status. Stigmatisation follows the violation of a social norm. At an intra-personal level it is associated with feelings of guilt, shame, inadequacy, and a sense of devaluation. At an inter-personal level it allows those not affected (i.e. fertile) to feel morally and socially superior to those affected (Whiteford and Gonzalez, 1995). In Africa, infertility stigma is often associated with profound negative social repercussions including abuse, isolation, neglect, and humiliation (Omar et al., 1994; Yebei, 2000; Hollos, 2003).

Gerrits (1997) described the social isolation of infertile women among the Macua (Mozambique). In this society women who have not given birth are prevented from participating in the important traditions surrounding fertility and childbirth. Humiliation is reflected in the concerns of infertile women in the Gambia who feel they are a source of scorn and gossip (Sundby, 1997). Among the Shona in Zimbabwe, adult men and women are customarily called by the name of their eldest child (i.e. mother or father of [child's name]), but infertile adults are addressed by their own first name. This is a sign of disrespect (Runganga et al., 2001).

In the Ijaw society (Nigeria), as previously outlined, adult womanhood is traditionally attained through fertility and clitoridectomy. Infertile women are therefore prevented from entering this stage of maturity and are often marginalised. After their death they may not be buried in the land belonging to the community, as this would diminish the fertility of the soil (Hollos, 2003). The fact that death does not remove the stigma of infertility has been reported by others. In some regions of Tanzania, infertile women were traditionally not buried but left to decay in the woods (Nyman, 1977 *as cited in*: Bergstrom, 1992). In Southern Chad, infertile men and women are buried with a 'marker' to inform the ancestors that they had not been productive and should be excluded from re-incarnation (Leonard, 2002).

❖ *Marital Instability and Divorce*

In many African societies infertility is grounds for divorce or for men taking another wife (Ebomoyi and Adetoro, 1990; Omar et al., 1994; Sundby, 1997; Koster-Oyekan, 1999; Tilson and Larsen, 2000; Araoye, 2003; Hollos, 2003). Even if childlessness is not accompanied by domestic abuse or neglect, the need to reproduce frequently overrides love and affection between spouses, making divorce or polygamy inevitable (Okonofua et al., 1997; Hollos, 2003).

A study in Nigeria evaluated psychological trauma among 200 infertile women. Nearly 40% of male partners had extra-marital affairs, approximately one out of three husbands had taken another wife or was planning to do so, and 12% of women were planning a divorce (Umezulike and Efetie, 2004). According to Sundby (1997) a similar number of infertile women in the Gambia feared divorce or polygamy (44%).

A study from Uganda evaluated causes of marital instability as part of the acquired immune deficiency syndrome (AIDS) intervention program (Nabaitu et al., 1994). Infertility was identified as one of the leading causes of marital instability, together with alcohol abuse, migrant labour, and sexual dissatisfaction. Infertile women were accused of “eating their husband’s things for nothing”, and the husbands would be advised to abandon these wives and/or have children with other women. The woman too, however, would be encouraged to conceive through an extra-marital affair and to deceive her husband with regards to the paternity of the child.

Female infidelity in response to infertility has also been reported in studies from Mozambique (Gerrits, 1997) and from Nigeria (Ezumah, 2003), where this practice is referred to as “taking shelter” from the negative repercussions of childlessness.

For women, particularly, divorce may be associated with loss of social status and the risk of poverty (Okonofua et al., 1997; Tilson and Larsen, 2000). A divorced woman from a previously childless marriage may have limited prospects for remarriage unless she

moves far away, marries an older man who needs a caretaker, or enters into a polygamous relationship with a man who already has children (Okonofua et al., 1997; Hollos, 2003).

In societies where payment to the parents of the bride is customary, divorce usually requires the return of the bridewealth which may be a source of anger and hardship for the female relatives and may result in maltreatment of the infertile woman (Feldman-Savelsberg, 1994; Hollos, 2003). Among the Bangangte women in Cameroon, divorce is also associated with loss of access to land which is owned by (married) men. If childlessness does not lead to divorce, these women receive fewer gifts from their husbands than fertile co-wives and face poverty without the help and support from children (Feldman-Savelsberg, 1994).

The ethnobiographic study by Hollos (2003) in Southern Nigeria describes in some detail the fate of married, infertile women. The common experience is that of disrespect and maltreatment by their husbands, in-laws, co-wives and their children. Divorce is often inevitable and may be initiated by the woman in order to escape further insults. Divorced women usually return to the compounds of a male relative where they are often marginalised and have poor prospects of re-marriage. Women with secondary infertility who get divorced are separated from their child as it belongs to the paternal lineage. Only sons can truly secure a woman's place in old age as her right to reside in her deceased husbands' compound is conferred through her male offspring.

These findings are in keeping with an earlier study from Nigeria in which Orji et al. (2002) evaluated the social situation of 236 women with secondary infertility. Nearly 40% had a history of divorce. The commonest reason for divorce was abuse by the husband's family (78.3%), male polygamy (54.4%), and accusations of witchcraft (39.1%). The latter is based on the belief that infertile women are witches who have spirit children and who can prevent other women from conceiving (Koster-Oyekan, 1999; Orji et al., 2002). According to Okonofua et al. (1997) these beliefs are used to justify ostracism of infertile women.

In the matrilineal society of the Macua, Mozambique, it is often the woman's relatives who initiate the divorce (Gerrits, 1997). In this society kinship is traced through the maternal lineage and, unlike patrilineal societies, women get custody of children after a divorce.

❖ *The Male Perspective*

Barker and Ricardo (2005) conducted a recent and comprehensive review on the construction of masculinity among young men in sub-Saharan Africa in the context of HIV/AIDS, conflict, and violence. The review was presented as a working paper from the Social Development Department of the World Bank. While the paper emphasised the plurality of masculinities in sub-Saharan Africa, it identified that a degree of financial independence through employment or income and the subsequent start of a family were chief requirements for manhood in Africa. The widespread custom of paying a bride price made financial means a pre-requisite for the latter. The authors noted that lack of work or income could have a profoundly negative effect on a man's social recognition and sense of manhood, and 'trap' young men in their position as boys. It would appear from the above that fertility is similarly central to the construct of manhood in Africa, but the possible consequences of infertility were not further discussed in the paper.

Although there is little doubt that women carry the main burden of the inability to conceive, little is known about the male perspective of infertility in Africa (van Zaandvoort et al., 2001). Like women men may also be trapped by gender stereotypes and social norms which equate masculinity with fertility, sexual prowess and faultlessness, and which deny men access to domestic tasks and child care (Gannon et al., 2004; Montgomery et al., 2005; Folkvord et al., 2005). Such stereotypes are likely to influence their own reproductive health and that of their female partner(s) (Varga, 2001; Barker and Ricardo, 2005). A few reports indicate that male infertility, where diagnosed and acknowledged, is a shameful and dreaded condition (Savage, 1995; Yebei, 2000; Runganga et al., 2001; Inhorn, 2003b). Most of what is known about the male experience of infertility is derived from female informants or by extrapolating from women's experiences (Inhorn and Buss, 1994). The need for further research on the effect of

infertility on the reproductive health of men in Africa and in other developing regions has been acknowledged (Mbizvo, 1996; Wang, 1999; van Zaandvoort et al., 2001).

❖ *Social Consequences of Infertility in South Africa*

There are few published data from South Africa pertaining to the experiences and social consequences related to infertility. Limited insight can be derived from three rather short publications in the 1970s. Freedman (1972) discussed ‘Aspects of Bantu ¹ domestic life in relation to some gynaecological conditions’. The author noted that marriage commonly involved the payment of a bride price and that high fertility rates were desired in order to continue the patrilineage. Infertile women were frequently despised and at risk of divorce. No further details or discussion regarding these findings are given, and the geographical region from which the data were derived is not stated.

Similar observations were recorded in two other reports. Brenner (1976) emphasised in an analysis of the causes of pseudocyesis that black women derived their main value from their fertility and that barrenness required the woman’s family to repay the bride-wealth or to provide another bride. These observations were based on the history of 21 women who presented with pseudocyesis to a maternity hospital in Soweto, a large low-resourced community outside Johannesburg. In a discussion on obstetrics and traditional health care among the Zulu, Gumede (1978) indicated that childbearing and infant care were the two ‘sacred’ duties of women in an African society and that sterile women faced contempt and unhappiness. No insight can be derived from the publication as to how and where this information was collected.

These findings are in keeping with some of the studies from other African countries already described. This would suggest that black women in South Africa had or have similar social experiences relating to the inability to conceive as women in other African countries. Any conclusions that can be derived from these three reports are, however, limited by the fact that two of the authors did not present, or refer to, any original data.

¹ Outdated terminology applied to black Africans during the time of apartheid

The relative absence of studies from South Africa in this area is perhaps surprising. It is possible that some studies have been conducted within the domain of the social sciences and published in sources which have not been accessed for this review. These publications are, however, not listed in the standard search engines for health care-related peer-reviewed literature and are not referenced in any other publication cited in this reviewed. They are therefore not immediately accessible to the health care profession and have not impacted on the delivery of infertility-related health-care.

Another explanation may relate to the international politics during the years of apartheid in South Africa. Several of the studies presented in this literature review were conducted by eminent researchers from the developed world in collaboration with local researchers in various African countries. During the years of apartheid South Africa was excluded from this form of collaboration. An alternative explanation is that infertility may not have attracted the interest of researchers in South Africa who were focused on other reproductive health problems such as contraception and population growth control. According to a review of the activities in many of the academic departments in the pre-1994 era this latter explanation seems, however, unlikely (personal communication).

1.2.6. Health-Seeking Behaviour and Health Care

Infertility-related health-seeking behaviour is shaped, among other factors, by the perceived causes and the social consequences of involuntary childlessness. Driven by the hope and need to conceive, the search for treatment is frequently ongoing and never-ending (van Balen and Gerrits 2001; Koster-Oyekan, 1999). Most of this search is undertaken by women who, as outlined above, are usually blamed for non-conception and who carry the main burden of the social consequences of childlessness (Mbizvo et al., 1984; Inhorn and Buss, 1993; Sundby, 1997). Failure to seek help may result in accusations of selfishness (for not wanting to contribute to the patrilineage) and irresponsible behaviour (Richards, 2002).

The role of men in the health-seeking process is less well described and requires further research. Existing information would suggest that men are, at best, peripherally involved.

According to studies from Egypt, Mozambique, and the Gambia men rarely accompany their wives and are also not asked by health care providers to attend for consultations (Inhorn and Buss, 1994; Gerrits, 1997; Sundby et al., 1998). It is, however, likely that men play at least a 'permissive' role in the health-seeking process as they often assume authority over all reproductive matters affecting the couple (Sundby, 1997; Varga, 2001).

Most studies evaluating infertility-related health-seeking behaviour demonstrate that women (and at times men) access both traditional and modern health services and in both health sectors infertility is a leading cause for consultation (Dillon-Malone, 1988; Inhorn and Buss, 1994; Shai-Mahoko, 1996; Gerrits, 1997; Sundby, 1997; Koster-Oyekan, 1999; Leonard, 2002; Stekelenburg et al., 2005). Different service providers may be accessed consecutively or concomitantly. Although such health-seeking behaviour may appear haphazard, it often follows a rational strategy based on the presumed cause of non-conception and modified by the accessibility of health systems (in terms of cost and distance to travel) and by the reputation of individual health care providers (Gerrits, 1997; Okonofua et al., 1997; Leonard, 2002; Stekelenburg et al., 2005).

According to an anthropological study in Nigeria, infertility may be managed by a number of different traditional healers (Koster-Oyekan, 1999). Local reproductive health specialists called 'olomo wewe' ('owner of small children') and herbalists offer herbs, powders, and medicinal soaps to treat different causes of non-conception. Spiritual and witchcraft-related causes of infertility are managed by the 'babalwo' ('priest'). Treatment involves sacrifices offered by the infertile woman to deities or ancestors as well as various ceremonies to lift evil curses. Linked to these interventions are preventative strategies which include charms, herbs, and the adherence to cultural taboos. A further preventative strategy is the avoidance of contraceptives and vaginal speculum examination as these are believed to be possible causes of infertility (Koster-Oyekan, 1999).

Among the Sara in Southern Chad, infertility-related health-seeking behaviour is referred to as 'looking for children' and 'doing research' (Leonard, 2002). At the outset of this

'research' the cause of infertility has to be identified - often from a multitude of possibilities. Infertility secondary to social discord is managed through the traditional health system. Interventions involve reconciliation ceremonies, food offerings, and ritual cleansing. In contrast, help is sought from the biomedical sector for most of the somatically expressed causes of infertility (such as infections, worm infestation and a 'dirty' womb).

In the Gambia, Marabout healers play an important role in providing infertility-related health care (Sundby, 1997). Interventions are usually based on medicinal drinks and amulets containing writings from the Koran. Other aspects of traditional health care involve spiritual healers, herbalists, fortune tellers, and visits to sacred places.

Several other studies describe the important role that herbs, medicinal drinks, amulets, cleansing rituals, spiritual and religious healers play in the management of infertility in Africa (Ebomoyi and Adetoro, 1990; Gerrits, 1997; Slobin, 1998; Yebei, 2000; Seybold, 2002). Collectively these studies indicate that, although traditional health systems may differ in their individual context and in the beliefs upon which they are built, their overall role and structure is remarkably similar throughout the continent (Sundby, 1997).

Infertility also places considerable demands on the often sparse resources of the biomedical health sector (Belsey, 1976; Stewart-Smythe and van Iddekinge, 2003). According to studies from Kenya, Egypt, Nigeria, the Gambia, and South Africa, infertility is either the leading cause or a very common reason for gynaecological consultations (Mati et al., 1973; Bergstrom, 1992; Inhorn and Buss, 1993; Okonofua, 1996; Sundby et al., 1998; Stewart-Smythe and van Iddekinge, 2003).

This demand on the modern health sector may, however, only represent the tip of an iceberg as some studies have indicated that less than half of infertile participants accessed modern health care (Gerrits, 1997; Sundby, 1997). A systematic evaluation of barriers to modern infertility services is mostly lacking. Only one such study has been identified. This demonstrated that the reasons why infertile women in the Gambia did not seek help

included not knowing where to go, the unwillingness of their partner to be investigated or to pay for consultations, and lack of trust in the biomedical health sector (Sundby et al., 1998).

In many African countries modern health services, especially in the public health sector, suffer from inadequate resources, which limit diagnostic and therapeutic options and render management unsystematic and inconsistent (Gbadegesin, 1993; Gerrits, 1997; Sundby, 1997; Leonard, 2002). Continuity of care is hampered by the change of health care providers and by the distance of travel between home dwellings and hospitals (Sundby et al., 1998). Comprehensive health care facilities, if they exist at all, are usually centred in one or very few public health hospitals or in the private sector (Serour et al., 1991; Sundby et al., 1998). Facilities at other hospitals are often rudimentary and do not extend beyond the use of antibiotics, hormonal contraceptives in case of menstrual irregularities and, at best, surgery for tubal disease or uterine fibroids (Gerrits, 1997; Leonard, 2002). Prescribed medication is often unavailable. In addition, women frequently appear to lack information and understanding of medical interventions (Gerrits, 1997).

Given the limitations of modern biomedical interventions in low resource settings, many authors highlight the importance of preventative health strategies (WHO, 1987; Wagner and St Clair, 1989; Leke et al., 1993; Sciarra, 1993b; Okonofua, 1996; Sundby et al., 1998; Geelhoed et al., 2002; Okonofua, 2003). The high prevalence of infection-related causes of infertility appears to represent a further argument in favour of prevention rather than intervention. If successful, preventative health care could reduce the reproductive health burden secondary to childlessness considerably. There are, however, two caveats. Firstly, prevention will not help the many men and women suffering from infertility in Africa today (van Balen and Gerrits, 2001; Mati, 2004). Secondly, lessons learned from the HIV/AIDS epidemic have demonstrated that effecting changes in reproductive behaviour is difficult and expensive. Perhaps the health campaigns geared at addressing the risk factors for HIV/AIDS may, ultimately, reduce the current high infertility prevalence in Africa.

Apart from seeking help from traditional and modern health care providers, women employ strategies in dealing with their fertility problem, which are not related to the health sector. These include feigning pregnancies and miscarriages to avoid the worst of the stigma, adopting or fostering children (often from relatives) and, as already described, making new sexual contacts with or without the knowledge of their male partners (Savage, 1992; Gerrits, 1997; Sundby, 1997; Chikovore and Mbizvo, 1999; Yebei, 2000; Hollos, 2003). It has been reported that men too have found it necessary to avoid the stigma of infertility by employing similar strategies such as claiming pregnancies with other women and even by transferring sexual rights to a male relative or a traditional healer (Savage, 1992; van Zaandvoort et al., 2001; Yebei, 2000).

It is evident that infertility-related health care and health-seeking behaviour in many African countries is associated with a plethora of options (Sundby, 1997). As long as traditional beliefs of health and disease persist, there will be a demand for traditional health care. It has furthermore been argued that this persistence of traditional beliefs and health care is sustained by the lack of adequate biomedical health facilities in resource-poor communities. In this setting the success of biomedical interventions is often no higher than that of alternative treatment strategies (Gerrits, 1997; Leonard, 2002).

1.2.7 HIV/AIDS and Infertility

The onset of the HIV/AIDS pandemic in Africa in the 1980s has compounded the problem of infertility. There is an inter-relationship between the two conditions. HIV/AIDS and infertility share similar risk factors and are driving forces for each other (Favot et al., 1997; Ikechebelu et al., 2002). Both conditions are associated with negative social consequences such as stigmatisation and socio-economic deprivation while creating contrasting social dilemmas - parents without children on the one hand and children without parents on the other. In addition, HIV infection remains a prominent barrier to available infertility services. In this section the interaction of HIV/AIDS and infertility in Africa and the associated treatment dilemma is reviewed.

❖ *The Impact of HIV/AIDS on Infertility*

The effect of HIV-1 infection on human fertility in Africa has been evaluated in a number of population-based studies, among cohorts of infertile women, and among women attending antenatal clinics (Schrijvers, 1991b; Favot et al., 1997; Gray et al., 1998; Glynn et al., 2000; Ikechebelu et al., 2002; Hunter et al., 2003). The observation that HIV infection is associated with reduced fertility is a consistent finding, and pregnancy rates in HIV-positive women are between 16% and 55% lower than those of non-infected women. This raises the question what comes first in causality: HIV or sub-fertility/infertility?

There are a number of mechanisms through which HIV infection may reduce human fecundity. Several researchers have reported an increased clinical and pre-clinical pregnancy loss in HIV infected women (Gray et al., 1998; Zaba and Gregson, 1998; Gregson et al., 1999; Lysterly and Anderson, 2001). Brocklehurst and French (1998) conducted a meta-analysis of studies from both the developing and the developed world which evaluated the risk of miscarriage in HIV-positive women when compared to healthy controls. The odds ratio for spontaneous miscarriages in the presence of HIV was 4.05 (95% confidence interval 2.75 – 5.96). According to Loko et al. (2005) the risk of fetal loss in HIV-positive women increases as CD4 counts decrease. The authors derived this observation from a study conducted in Abidjan, Cote d'Ivoire, which involved 473 HIV-infected women of childbearing age.

HIV infection increases the risk of tubal factor infertility as it predisposes to pelvic inflammatory disease (Zaba and Gregson, 1998; Lysterly and Anderson, 2001). Advanced HIV infection can cause weight loss-related anovulation and amenorrhoea in women. Low CD4 cell counts in men may be associated with hypogonadism (characterised by a decrease in serum testosterone levels and increased sex hormone-binding globulin) and impaired spermatogenesis (Zaba and Gregson, 1998; Lysterly and Anderson 2001). Although these patho-physiological changes largely account for the reduced fecundity in HIV-positive individuals, behavioural factors may also contribute. These include use of

condoms, sexual abstinence, and illness-related reduction in sexual frequency (Zaba and Gregson, 1998).

❖ *The Impact of Infertility on HIV/AIDS*

While HIV contributes to the high prevalence of infertility in Africa the reverse may also be true. The relationship between infertility, sexual behaviour, and HIV infection has been the subject of some recent studies. In a study in Nigeria, approximately 2000 infertile women were screened for HIV infection between 1995 and 2000 (Ikechebelu et al., 2002). Women who tested HIV-positive (6.8%) were significantly more likely to have had multiple sexual partners when compared to HIV-negative infertile women. Although the design of the study did not allow the authors to determine the timeframes between sexual behaviour, infertility, and HIV infection respectively, they concluded that the need to conceive resulted in unsafe sex behaviour among infertile women.

In an earlier study Favot et al. (1997) assessed HIV prevalence among 154 infertile women and 259 fertile controls in Tanzania. When compared to pregnant women, infertile women had a significantly higher HIV prevalence rate (18.25 versus 6.6%), were more likely to be in polygamous unions, had a higher number of sexual partners, and were less confident about the sexual fidelity of their current partner. The authors recognised the limitations of a cross-sectional study in determining the causal relationship between HIV and infertility but indicated that their results were in keeping with anthropological studies assessing the impact of infertility on marital stability. They recommended that infertility should be recognised as one of the driving forces of the HIV/AIDS pandemic.

In an ethnographic study from Botswana, Upton (2002) explored the cultural construct of infertility, HIV, and sexual behaviour. Among the Tswana both infertility and HIV are interpreted as an illness of the female blood which may be incurable. As infertility is a feared condition which is commonly attributed to modern contraception, many informants considered condom use dangerous. This included people who were employed within biomedical health services. According to belief, men can contract the illness from

women but can achieve cure through sexual intercourse with young women or girls. As virgins are believed to offer the most effective cure this practice has been referred to as the “virgin cleansing myth”. The existence of this myth and practice has also been reported from Mozambique and South Africa (Leclerc-Madlala, 1997; Bamba, 1999; Andersson et al., 2004).

❖ *Infertility Management in the Setting of HIV/AIDS*

Recognising infertility as a risk factor for HIV acquisition and as a driving force of the spread of the infection is of particular importance as the universal advice of “safe sex” does not address the needs of the involuntarily childless and will thus do little to contain the spread of the pandemic in this setting.

What does address the needs of the infertile couple in the setting of the HIV pandemic? Clearly access to biomedical infertility interventions may help the HIV-negative couple to conceive without the need to seek additional sexual contacts, which are associated with risk of exposure to HIV. The infertility management of HIV-infected individuals, however, poses many dilemmas and challenges.

At the beginning of the HIV/AIDS pandemic, HIV infection was considered a contra-indication to infertility management. This approach was based on concerns related to HIV infection of the offspring and of a non-infected partner, to the future morbidity and reduced lifespan of the prospective parent(s), and to the risk of accidental HIV transmission to staff and contamination in a gamete laboratory (Ryan, 2001; Ethics Committee of the American Society of Reproductive Medicine (ASRM), 2002).

We have witnessed an extensive debate in recent years both in the professional and lay arenas as to whether it is justified to exclude HIV-positive couples from infertility treatment. This debate has been largely initiated by the advent of anti-retroviral treatment, which is associated with improved patient survival and reduced risk of vertical transmission. These changes largely nullify the reasons for which infertility treatment has been traditionally withheld (Ryan, 2001; Ethics Committee of the ASRM, 2002). Anti-

retroviral therapy may also reduce the possible risk of cross-contamination in a gamete laboratory, as it reduces the viral load in biological samples of HIV-positive individuals. The risk of accidental infection of staff or the contamination of non-infected biological samples in the laboratory is, in all likelihood, very low provided good laboratory standards are practised (Lyerly and Anderson, 2001). As an additional precaution, the use of dedicated laboratory facilities in the handling of biological material from HIV-positive individuals has been recommended (Englert et al., 2001; Lyerly and Anderson, 2001).

The impact of anti-retroviral treatment on the infertility debate has been paralleled by the development of clinical strategies which reduce the risk of HIV transmission to the HIV-negative partner in sero-discordant couples. These strategies involve intra-uterine or intra-vaginal insemination in cases of HIV-positive women. If the male partner is HIV-positive a more complex approach is required which includes sperm-preparation techniques and anti-retroviral agents to reduce viral load in the seminal fluid and to offer exposure prophylaxis to the woman (Marina et al., 1998; Lyerly and Anderson, 2001). The role of intra-cytoplasmic sperm injection into the oocyte, as part of assisted fertilisation techniques, has also been explored as it has been suggested that HIV-1 cannot infect sperm cells (Pudney et al., 1998; Sauer, 2003).

Based on these developments, the categorical exclusion of HIV infected individuals or couples from infertility services has increasingly been challenged (Minkoff and Santoro, 2000; Englert et al., 2001; Gilling-Smith et al., 2001; Lyerly and Anderson, 2001; Sauer, 2003; Daar and Daar, 2006). In 2002 the Ethics Committee of the ASRM stated that individuals and health care workers would not be “acting unethically in proceeding with reproduction if they have taken all precautions to prevent disease transmission” and provided the parents “are prepared to love and support the child, regardless of the child’s medical condition”. Reproductive assistance would, however, be unethical in the absence of the clinical and laboratory resources needed to effectively care for HIV-positive couples who wish to conceive. Lack of resources should be an indication to refer couples to appropriately resourced centres.

It is interesting, but perhaps not surprising, that the debate on HIV and infertility treatment has been argued almost exclusively in the developed world while the burden of both conditions is overwhelmingly carried in Africa. The relative absence of this debate in countries most affected is due to several factors including the overall lack of health resources and a largely negative attitude towards reproduction in HIV-positive individuals (de Bruyn, 2004). This highlights an urgent requirement to explore and address the fertility issues of those who are HIV-positive, those who are infertile and those who are affected by both conditions. Although there are no easy solutions, continuing silence on these issues will only perpetuate the tragic cycle between infertility and HIV.

1.2.8. Social Consequences of Infertility in a Global Perspective

The social consequences of infertility appear globally to be strongly linked to societal norms regarding gender roles and childbearing. Marriage and childbirth is clearly the prescribed norm for most adults in the developing world. Violation of this norm carries social consequences and the literature describing these consequences in African countries has been presented. Interestingly, similar consequences have been reported from developing countries elsewhere in the world.

Papreen et al. (2000) evaluated the experience of living with infertility among urban slum populations in Bangladesh. In this society marriage is patrilocal, which implies that women move into the homes of their in-laws. Children, and especially sons, represent the fulfilment of marriage, the continuation of the family line and security in old age. In the absence of children women are usually blamed for non-conception and often suffer from stigmatisation, domestic neglect, divorce, and abuse. According to some informants, infertile women are believed to create misfortunes such as cholera epidemics. Men may also suffer loss of social status and may be marginalised in the community.

Son preference is reported from many other Asian countries and is invariably linked with gender inequality and low female status (Lee and Sun, 2000; Hussain et al., 2000; Winkvist and Akhtar, 2000; Bharadwaj, 2003). According to a report from Indonesia,

payment of a bride price is still common and allows men to claim ownership of women and authority over the household (Setiawan, 2004). In this situation, as in the African context, for many women their children, and sons particularly, are their main avenue to social status and certain resources.

Winkvist and Akhtar (2000) reported that women in Pakistan were often married at a young age without the opportunity of education. Women who failed to conceive were allocated the lowest status within the family and were subjected to disrespect, verbal and physical harassment, food deprivation, and increased workloads (which may include work for second wives). Women with higher socio-economic status and better education were, however, less likely to be mistreated in case of infertility.

Negative social consequences of infertility do not only occur in the developing world. Stigmatisation and social isolation may also form the experience of women and men in the Western industrialised world, where relatively recent studies indicated that infertile people feel 'different', 'isolated', 'worthless', and see themselves as deviant and as 'not fitting in' (Menning, 1980; Sandelowski, 1988; Whiteford and Gonzalez, 1995; Jirka et al., 1996). They may feel labelled by others as selfish and uncaring, and in turn often see the outside world as threatening, antagonistic, and intolerant (Sandelowski, 1988; Raphael-Leff, 1992; Becker and Nachtigall, 1994). In addition, numerous studies have described the negative emotions and reactions which are commonly associated with the inability to conceive and which include, among others, anger, anxiety, depression, shock, hostility, grief, loss of self-esteem, guilt, surprise, and denial (Menning, 1982; Bernstein et al., 1985; Golombok, 1992; van Balen and Trimbos-Kemper, 1993). It follows that for many people in the developed world there is considerable suffering inherent in the experience of infertility.

Although negative social consequences exist globally they appear less threatening in industrialised countries when compared to the developing world (van Balen, 2000). There are two possible explanations for this difference. The norm to reproduce may be less

powerful in the developed world or alternatively the community/society reacts less vehemently to the violation of this norm. Data exist in support of both factors.

In recent decades several social changes, including better education and career development for women, increasing materialism and individualism, easy access to safe and effective contraception, and a shift towards non-marital relationship structures have altered the role of women, and to a lesser degree that of men, in modern industrialised societies (Poston and Rogers, 1988; Becker and Nachtigall, 1994; Christie, 1998; Population Reference Bureau, 2004). In these societies parenthood continues to be an important life goal, but it may not be the only life goal or not the most important one (Whiteford and Gonzalez, 1995; Daniluk, 1997; Sundby, 2000). This is reflected in a considerable reduction in total fertility rates, which have fallen to below the replacement rate in almost all developed countries (Population Reference Bureau, 2004).

Evidence for greater tolerance of infertile people is found in a study by van Balen et al. (1996). The authors investigated how 164 long-term infertile couples perceived the reaction of their social environment to their infertility in the Netherlands. The participants were asked to score this reaction on a 5-point scale (1 = 'very dismissing'; 5 = 'great deal of support'). The mean score was 3.6 and no significant difference was found between male and female respondents. The authors concluded that in general the social environment of infertile couples showed a positive and supportive response to the fertility problem.

These findings are in keeping with a subsequent study conducted in the USA, in which social interactions related to infertility were measured through the Unsupportive Social Interaction Inventory (Mindes et al., 2003). This 24-item inventory measures stressor-specific unsupportive social interactions. Each of the 24 items reflects unsupportive or upsetting responses to a life stressor (i.e. infertility), and respondents rate the degree with which they have experienced a particular response on a 5-point Likert scale (0 = none, 4 = a lot). The authors recruited 123 infertile women from two University medical centres, two private fertility clinics and through a national infertility support organisation. Most

participants had experienced low levels of infertility-specific unsupportive social interactions (mean score 1.22, SD 0.86).

The existing data make it tempting to summarise the situation as follows: Infertility represents a global violation of the norm to reproduce. In the developed world this norm is less strongly prescribed due to social changes which have modified roles and life goals for men and women. Although stigmatisation does exist, the response from the social environment is more supportive and less condemning when compared to developing countries.

There is, however, one important caveat to this conclusion: The Western industrialised literature which has addressed the psychological and social implications of infertility has, to date, focused on white, educated, middle class women (Hirsch and Mosher, 1987; Downey and McKinney, 1992; Berg, 1994; Whiteford and Gonzalez, 1995; Greil, 1997). It is likely that people of colour, immigrants, and those with poor socio-economic backgrounds have different experiences. What these differences are and how they relate to the experiences of men and women from the developing world remain to be established. Similarly, more research is needed on the modifying effect that education and social class may have on the experience of infertility in developing countries.

1.2.9. The Globalization of Assisted Reproductive Technologies

Assisted reproductive techniques (ART) play an ever increasing role in the management of infertility. In the USA over 100 000 ART treatment cycles were conducted during the year 2000 resulting in 35 000 live born neonates (Society for Assisted Reproductive Technology and the ASRM, 2004). In several European countries 1% or more of live births are attributable to ART (van Balen, 2001; Andersen et al., 2005). The success of ART in the industrialised world is based on sound research, good resources, a rising prevalence of infertility (especially primary infertility), and, usually, a common cultural and religious background of physicians and patients (van Balen and Gerrits, 2001; Lunenfeld and Van Steirteghem, 2004).

Although IVF clinics have flourished in the industrialised world, the management of infertility through ART is not without problems. Limitations include treatment failure, high cost, and in some countries restrictive laws and regulations which govern this biotechnology (Menning, 1980; van Balen et al., 1999; Sundby, 2000; IFFS Surveillance, 2004). As a consequence, up to 50% of couples treated may remain childless, and many others may be unable to access this technology (Menning, 1980; Sundby, 2000).

While debate continues about the use of ART in countries in which these technologies have originated, the export of ART into the developing world has been particularly problematic and controversial. The demand for ART in the developing world is, in principle, enormous if we consider the high prevalence of infertility, the nature of the underlying pathology (which limits the success of other treatment options), and the considerable human suffering associated with involuntary childlessness (Inhorn, 2003a).

In reality the barriers to ART are considerable. The cost of treatment, which is already problematic in well-resourced countries, is even more difficult to negotiate against a backdrop of poor resources and competing health needs. Next to cost there are cultural barriers. In Latin America and in many Islamic countries religious doctrine has severely restricted the use of ART (Serour et al., 1991; Inhorn, 2003a; Lunenfeld and Van Steirteghem, 2004). In India normative values of Hindu marriage are similarly in conflict with ART, since the involvement of a third party for childbearing publicly violates the boundaries of marriage and compromises the process of conception (Bharadwaj, 2003). In a review of the role of bioethics in the developing world Qiu (1993) emphasised that in many non-Western countries cultural barriers may exist between physicians, who were trained in Western medicine and who have often adapted to Western culture, and their patients, who uphold traditional belief systems and who are unfamiliar with the manner and technology of 'modern' medicine.

Geographical barriers are more prominent in developing countries when compared to the industrialised world, since ART can, at best, be centred in a few urban units. Additional concerns include the lack of an overall infrastructure for ART (i.e. lack of staff and

technical expertise, shortages in supplies and electricity) and physical risks (ectopic pregnancies, multiple pregnancies, ovarian hyperstimulation syndrome), which are a threat to women's lives and which take up additional resources through, for example, the care of premature infants (Okonofua, 1996; Inhorn, 2003a).

Despite these barriers ART has spread to many developing countries. Access, however, remains restricted and is often only open to a small social elite who can pay for high-cost treatment in private clinics (Inhorn, 2003a; Lunenfeld and Van Steirteghem, 2004). Concern has been expressed that this situation is unlikely to change in the near future, thereby leaving the majority of the infertile population in developing countries without viable treatment options and with often inadequate political willingness of their governments to find effective solutions (Inhorn, 2003a; van Balen and Gerrits, 2001). Based on this situation the observation made by Lunenfeld and Van Steirteghem (2004) that the medical profession has failed to develop less expensive but successful infertility interventions, and that "a more serious commitment today to increasing access to better quality health care services, including infertility treatment, would be a major contribution to global solidarity and equity" appears justified.

The task at hand is neither to condemn the role of ART in developing countries as socially inappropriate and economically unfeasible, nor to consider it the panacea of infertility management. Instead, appropriate health care strategies and solutions need to be found to translate the theoretical benefits of ART in the developing world into real advances in infertility management. One such strategy is to increase our understanding of the construct, experiences, and health-seeking behaviour related to infertility in non-Western societies. This understanding is of dual importance. It helps to narrow the gap between 'Western technology' and local culture, and it provides evidence for the impact that infertility has on the reproductive health of women and men. Since competing health needs will always exist, this evidence is paramount in justifying the allocation of sparse resources for infertility management. The research presented in this dissertation will hopefully contribute to this evidence and understanding in South Africa.

1.3. AIM AND OUTLINE OF THE DISSERTATION

This dissertation presents a series of studies which address the central research question of how men and women experience, construct, and respond to infertility. The overall goal of the research was to improve our understanding of our patients' perspective of infertility and infertility management and ultimately to integrate this understanding into infertility-related public health services in South Africa.

Chapter 2 outlines the setting in which the studies were conducted and presents some general considerations about the research methods. Chapter 3 describes the first original study in which women's reproductive-health knowledge with regard to fertility and infertility, their health-seeking behaviour, and their experiences related to involuntary childlessness were explored utilising qualitative research methods. Chapter 4 reports on a study which assessed psychological distress in women suffering from couple infertility through the use of a standardised instrument, the Symptom Checklist-90-R. In the qualitative study described in chapter 5, clinic-related barriers to treatment adherence were explored in treatment compliant and non-compliant women.

Chapters 6 and 7 address the male perspective of involuntary childlessness. Chapter 6 describes a qualitative study which assessed men's reproductive health knowledge, health-seeking behaviour, and experiences related to involuntary childlessness. The assessment of psychological distress among men suffering from couple infertility utilising the revised Symptom Checklist-90-R is the focus of chapter 7.

Following these studies, which documented negative emotional and social consequences of infertility in both men and women, the reasons why infertile couples wanted to conceive were assessed through the use of a standardised instrument, the parenthood-motivation list. This study is presented in chapter 8.

As the studies underpinning this dissertation progressed, so did the spread of the HIV/AIDS epidemic in the country, and a steady increase in the number of patients who tested HIV-positive at our infertility clinic was observed. Some of the issues surrounding HIV infection and infertility treatment were explored. Chapter 9 describes in a cohort of HIV-negative, infertile couples the knowledge of HIV and attitudes to fertility and infertility treatment in the presence of HIV infection. It also seeks to explore whether an association existed between these attitudes and parenthood motives (Chapter 8). Experiences and perspectives of HIV-positive, infertile men and women who unsuccessfully tried to access our infertility service are presented in chapter 10.

In the final chapter (chapter 11) the conclusions derived from this research are presented and recommendations are made for the delivery of infertility-related reproductive health care and for future research.

CHAPTER 2

RESEARCH SETTING AND METHODS

2.1. INTRODUCTION

Each study presented in this dissertation contains a description of the research methodology applied. It is the aim of this chapter to describe the research setting, to provide some background information on the infertility service as contextual information, and to outline aspects of data collection and processing which are common to all or some of the individual studies. A brief discussion of qualitative research methods is presented, since these methods are comparatively new in the research armamentarium of the health scientist. In addition, the research ethics are discussed, and constraints and possible limitations of the research are considered.

2.2. RESEARCH SETTING

In South Africa the public health system is structured into primary, secondary, and tertiary level care. This system offers health care to all patients who cannot afford private facilities. Patients who can access private care (due to medical insurance or a monthly family income above a prescribed certain level) may still enter the public health system but pay higher fees when compared to patients with no medical insurance or lower income. Although in the Cape Town metropole some preliminary infertility evaluations can be conducted in secondary care facilities, the majority of infertile couples are referred to tertiary care from primary health services or general practitioners prior to any infertility-related investigations.

Most of the patients within the public health system are from local, low-resourced communities. A population census conducted in 2001 established a population count in the city of 2.9 million. The community of Cape Town consists of three major ethnic groups. Approximately half of the population is of mixed ancestry (locally referred to as 'coloured'), while 31.7% are black Africans and 18.8 % are white. The comparatively low number of black Africans is a legacy of the apartheid policy, which prevented their migration to the city, unless for recognised employment. The languages most commonly spoken are Afrikaans (41.4%), Xhosa (28.8) and English (27.9). Xhosa is the local black African language, however, many black Africans also speak English. The coloured and white population mostly speaks Afrikaans and/or English. The majority of citizens are Christians (85%) and 13% are Muslims (Statistics South Africa, 2001).

All studies in this dissertation were conducted at the infertility clinic of Groote Schuur Hospital and the Faculty of Health Sciences of the University of Cape Town. This clinic is a tertiary referral clinic within the public health system. It is situated in the outpatients building of Groote Schuur Hospital. Together with the gynaecological endocrine service, the mature women's clinic and the recurrent miscarriage clinic it operates under the umbrella of the Reproductive Medicine Unit of the Department of Obstetrics and Gynaecology. In two of the studies described in this dissertation, primary care facilities in the Cape Town metropole (family planning clinics and midwife run obstetric units) were utilised as additional sites for the recruitment of control subjects.

2.2.1. The Infertility Service

The Reproductive Medicine Unit offers a comprehensive infertility service comprising endoscopic surgery, ovulation induction, artificial insemination, and assisted reproductive techniques including assisted fertilisation.

The referral of new patients to the infertility clinic is governed by guidelines rather than strict referral criteria. These guidelines specify that the criteria for the diagnosis of infertility have to be fulfilled, that the male partner is willing to participate, and that the woman is younger than 42 years of age. The couple should be married or in a stable

relationship of two years duration with no more than one live child in union. Children from previous relationships are not an exclusion criteria for infertility treatment, provided the couple has the necessary resources to care for all their off-spring.

Patients who are newly referred to the infertility clinic receive appointments for their first visit in chronological order of referral. The waiting time for this first appointment is ten to twelve weeks. At the first clinic visit the couple is seen by one of the professional nurses working within the service. Basic medical and socio-demographic information is obtained, and the couple is scheduled for routine infertility investigations. These include mid-luteal phase serum progesterone measurement, semen analysis, syphilis serology, and rubella status in the woman. All patients receive HIV pre-test counselling and undergo HIV-testing subject to patient consent. In addition, early follicular phase FSH and estradiol measurement is conducted in all women aged 37 years or older to determine ovarian reserve.

Following these investigations, the couple is asked to return for a second consultation at the clinic where they are seen by one of the clinic doctors. Further management includes an assessment of tubal patency by laparoscopy or hysterosalpingography, as well as any other diagnostic procedures based on the results of the initial investigations. Once the underlying diagnosis has been established, treatment options are discussed with the couple.

All infertility patients contribute to the cost of treatment according to their income range. While the various treatment modalities are subsidised by the State, the cost of medication for ovulation induction is not included in this subsidy because of budget constraints and has to be paid by the patients. The low income of many couples within the service can therefore make access to assisted reproductive techniques prohibitively expensive. The treatment outcome of the various interventions is subject to regular audit.

2.3. PATIENT RECRUITMENT AND DATA COLLECTION

The majority of informants who participated in the various studies were recruited from the infertility clinic at the time of their first visit prior to the informants meeting with any member of the medical team. In two studies informants were recruited at some point after their first clinic visit. In addition, two control groups were recruited from family planning clinics in the city (chapter 4) and from antenatal clinics at primary level care (chapter 6). Unless stated otherwise study participants were recruited consecutively but subject to the presence of a research assistant at the health care facilities

All interviews were conducted in a quiet and private environment at the infertility clinic or at the primary care facilities. Study participants were always interviewed alone, without the presence of their partner. This decision was taken because some of the studies sought to elicit information about domestic abuse, and it was anticipated that without the presence of their partners women, in particular, would speak more freely about their experiences with infertility. In the studies in which couples were recruited, data were collected from both partners in the same setting but consecutively and without giving individuals the opportunity to communicate with each other before both interviews were completed.

All data were collected in the informants' preferred language (Xhosa, English or Afrikaans) unless otherwise specified. The role and involvement of research assistants in the data collection is outlined in the individual studies. All in-depth interviews of the qualitative studies were audio-taped, transcribed and, if required, translated into English. Questionnaires utilised in the quantitative studies were translated into Afrikaans and Xhosa by multi-lingual health care professionals and then retranslated into the original English in order to ensure the same questions were asked in all three languages. All questionnaires and interview guides are presented in the Appendix. Information regarding data analysis is forwarded in the individual chapters.

2.4. QUALITATIVE RESEARCH METHODS

2.4.1. General Considerations

Qualitative research methods are well established in the social sciences where they form a central tool of inquiry. In contrast, they have played a more limited role in the health sciences where research is predominantly quantitative in nature (Jones, 1995; Pope and Mays, 1995). According to this quantitative approach the ‘best available evidence’ for patient care is derived from randomised, placebo-controlled trials which make use of statistical analysis of data to confirm or refute ‘significance’ of findings (Mann, 1996 *as cited in*: Royal College of Obstetricians and Gynaecologists, 1998; Bergsjö, 1999).

Increasingly, health scientists have, however, recognised that quantitative studies do not offer answers to all questions related to patient care (Jones, 1995; Pope and Mays, 1995; Aoun and Kristjanson, 2005). Randomised controlled trials allow us to establish, for instance, which infertility interventions are associated with the highest number of live births in couples suffering from tubal factor infertility. They do, however, not allow us to determine why patients who are apparently desperate to conceive drop out from biomedical treatment, as answers to this latter question will not be easily forthcoming by measuring or counting a number of variables. Although in theory every emotion and thought can be transformed to measurable entities, the insistence on a mathematical strategy to all research questions appears inappropriate (Bergsjö, 1999).

In contrast to quantitative research, which is limited to the domain of measurable variables, qualitative research seeks to explore the ‘unquantifiable, personal, in depth, descriptive and social aspects of the world’ (Winter, 2000). Barritt (*as cited in*: Creswell, 1998) emphasised that the rationale of qualitative research was ‘not the discovery of new elements, as in natural scientific studies, but rather the heightening of awareness for experience which has been forgotten and overlooked... . [This] can lead to better understanding of the way things appear to someone else and through that insight lead to improvements in practice’.

Qualitative research is not a single entity but contains a wide variety of research methods, which have emerged from five basic research traditions (Creswell, 1998). These five traditions comprise biography, phenomenology, grounded theory, ethnography, and case studies. While some researchers work strictly within the framework of one of these methodological traditions, others combine certain aspects. In addition, new frameworks for qualitative research continue to emerge and evolve (Trochim, 2004).

While a detailed review of qualitative research methods is beyond the scope of this chapter, some of the common characteristics will be outlined. Qualitative research typically involves small study cohorts, many variables, and an inductive research approach (that is using findings or observations to generate a hypothesis) rather than the deductive approach applied in quantitative research (formulating a hypothesis at the outset of research and using findings to confirm/refute this hypothesis). Research questions can be changed or modulated in the course of data collection in order to accommodate new themes that emerge in the course of the research. Studies are usually conducted in natural settings rather than in the experimental environment of quantitative research. Data collection commonly takes the form of interviews or group discussions in which the researcher does not try to be 'invisible' or neutral (as in most quantitative studies) but actively engages with the research participants to generate information-rich data. Such data are inherently diverse, non-standardised, and can be difficult to classify. It is the aim of the analytical process to provide coherence and structure to these data (Ritchie and Spencer, 1994; Turner, 1994; Jacelon and O'Dell, 2005).

The analysis of qualitative interview data is a complex process in which the researcher has to become fully familiar with or 'immersed' in the original interviews (usually captured on audio-tapes). Data are then broken up into many categories and sub-categories, which are coded or catalogued. The relationship between categories is explored, key storylines are identified, associations are evaluated, contexts are defined, and the data may be 'mapped' on charts or graphs (Jacelon and O'Dell, 2005). In the next stage of analysis categories are combined into broader topics, and in doing so data reduction may occur. Thereafter data are 're-assembled' according to various criteria

such as facts, time lines, or prevalence in order to build a logical chain of events and evidence, which allows interpretation. The extent and objective of this interpretation depends on the research method applied.

In the last phase of analysis the data are condensed and a detailed report or narrative is written (Burnard, 1991; Berg, 1994; Sandelowski, 1995; Creswell, 1998). In the narrative qualitative researchers often try to preserve some of the original accounts forwarded by the study participants (Berg, 1994). One method of doing this is through direct quotes (Sandelowski, 1994; Whiteford and Gonzalez, 1995). Quotes are common features in qualitative reports where they fulfil different functions, which comprise representing the 'truth', providing a specific example of a finding, and drawing attention to individual human experience which may be otherwise lost in the data. Generally speaking, quotes should be used to add a personal and dramatic component to the narrative without seeking to sensationalise (Sandelowski, 1994).

A further feature of a qualitative report is that it is comparatively devoid of numbers. Qualitative findings do not lend themselves to be presented in tables or figures, and simply counting how many participants said one thing or another would seek to draw quantitative conclusions from qualitative enquiry. Yet some numbers may be required to offer information on the magnitude or frequency of a finding or effect. Qualitative researchers tend to provide this information through verbal counting, using terms such as 'few', 'many' or 'often'. In order to reduce the vagueness of verbal counting and to add to the scientific rigor of a qualitative report, operationally defined verbal counting has been recommended (Sandelowski, 2001). This implies that words reflecting indeterminate quantities are numerically defined in the context of an individual study (Sandelowski, 2001).

2.4.2. *Qualitative Description*

All qualitative studies in this dissertation follow the method of qualitative description. Sandelowski (2000), an eminent scientist in the field of qualitative research and reproductive medicine working at the University of North Carolina, considered

qualitative description as particularly suitable in health research which seeks to establish the 'who', 'what' and 'where' of events or services such as 'What reasons do people have for using or not using a service?'

A study following qualitative description shares many of the features described above. One of its key characteristics is that it stays close to the original data or facts. The researcher will seek to account for and interpret the factual research findings in a way that most other people (both researchers and informants) would agree as being accurate. While some interpretation of the data is required, such interpretation is of low-inference when compared to other qualitative research methods such as grounded theory or phenomenology. This implies that the researcher does not seek to describe findings in a 'philosophical or highly abstract framework or system'.

The data in a qualitative descriptive study are typically collected through semi-structured, in-depth interviews. This term implies that a basic structure is applied to the interview, usually in form of an interview guide, which outlines the area to be explored without 'closing' the interview to new and unanticipated themes. Questions are open-ended and discussed in depth. Interviews are usually audio-taped and transcribed, while additional field notes may capture relevant observations which are not recordable through audio-tapes. Data analysis follows the principles outlined above with specific focus on summarising the factual content of the data. The final research report should convey this factual content in a coherent and succinct manner without requiring the researcher to develop abstract theories or to interpret the meaning of human behaviour.

2.4.3. Validity and Reliability

One of the criticisms often levelled against qualitative research is that it lacks both reliability and validity when compared to quantitative studies (Mays and Pope, 1995). Reliability and validity in turn are commonly interpreted as markers for the 'truth' in research. It is apparent from the definition of these terms (reliability = the degree to which an instrument measures the same way each time it is used under the same conditions in the same subject; internal validity = to measure what the experiment

purports to measure, i.e. the accuracy of measurement; external validity = the generalisability of findings to other settings) that reliability and validity are problematic concepts in qualitative research, as they appear to be *quantitative measures* of the *quality* of a study (Emden and Sandelowski, 1998; Winter, 2000; Golafshani, 2003).

Traditionally, qualitative researchers have sought to devise ways to demonstrate the reliability and validity of their work according to the above definitions. According to this approach, reliability and internal validity can be safeguarded if the raw data are meticulously recorded, and if data analysis is conducted independently by two different researchers who agree on the analytical process such as defining codes and the re-organisation of the data (Mays and Pope, 1995). Alternatively, or in addition, study participants can be involved in the data analysis, or they may be asked to assess whether the final narrative is a 'true reflection' of the interviews (Burnard, 1991; Mays and Pope, 1995). A further important method for demonstrating both reliability and validity in qualitative research is triangulation. In the process of triangulation the same evidence or supporting evidence is sought through different means and from different sources (including different researchers and their publications) and by demonstrating convergence of the different sets of data (Mays and Pope, 1995; Golafshani, 2003).

In this dissertation attention has been given to these traditional approaches in demonstrating reliability and validity of qualitative research. Raw data were captured as recommended above, but study participants or other independent researchers were not involved in the analytical process for reasons of confidentiality (study participants) and research resources (independent researchers). The narratives of the qualitative studies were, however, presented to the research assistants who were involved in the process of data collection and who confirmed that the reports accounted for the original interviews. The analytical process applied, namely that of descriptive analysis, further facilitates validity as it stays close to the raw data (Sandelowski, 2000). In addition, triangulation is repeatedly provided in this dissertation in that quantitative studies underpin the findings of qualitative research, accounts given by women are supported by those forwarded by

men (and *vice versa*), and, where available, supporting evidence generated by other researchers in the field is presented.

It must, however, be noted that there is considerable debate regarding the concepts of validity and reliability as markers for 'quality' in qualitative research (Emden and Sandelowski, 1998; Cutcliffe and McKenna, 1999). At the centre of this debate is the question whether the largely quantitative concepts of reliability and validity have a role in qualitative research and if not, how else to assess 'quality'. At the one end of this debate are researchers who uphold these concepts and who seek to demonstrate them through strategies outlined above. The other end of the spectrum is occupied by arguments which seek to make 'quality checks' – at least in the traditional sense – redundant, as these are interpreted as barriers to knowledge-dissemination and as ways of 'policing' social science through legitimising or not legitimising specific findings (Aguinaldo, 2004). Between these two ends of the debate are many researchers who argue that the 'quality' of qualitative studies cannot be demonstrated through quantitative criteria. Alternate criteria have been suggested and debated. These include, among others, credibility, trustworthiness, fairness, plausibility, the probable truth (in the understanding that no criterion can ever prove that a finding is completely valid), accountability, and the ethics of the inquiry and of knowledge dissemination (Emden and Sandelowski, 1999; Winter, 2000; Golafshani, 2003).

The question how best to measure 'quality' in qualitative research remains unresolved and the debate about which criteria, if any, provide evidence of 'good science' continues (Emden and Sandelowski, 1998; Winter, 2000). A satisfactory solution to this debate, if and when it is found, is likely to strengthen the role and perceived value of qualitative research in the health sciences.

2.5. RESEARCH ETHICS

Informed consent was obtained from all study participants. The purpose of the study was explained to each participant individually, and relevant written information about the individual studies was supplied in English, Afrikaans and Xhosa. All informants were assured that participation was entirely voluntary, that declining to participate would in no way influence their current or future health care, and that all information would be handled in an anonymous and confidential manner. All studies were approved by the Ethics Committee of the University of Cape Town, Faculty of Health Sciences. The permission to recruit informants from primary health care facilities was obtained from the relevant authorities.

2.6. CONSTRAINTS AND POSSIBLE LIMITATIONS OF THE RESEARCH

The research findings apply to the cohort of men and women from an urban, culturally heterogeneous community in South Africa who sought help from a tertiary infertility clinic within the public health system. These findings can therefore not be extrapolated to all infertile men and women in South Africa. It is possible that men and women who do not seek treatment or who live in other areas of South Africa differ in their experiences, knowledge, and health-seeking behaviour.

In the absence of data one can only speculate on the reality of infertility in different settings. Not seeking help may be a reflection of adjustment and acceptance of childlessness. Alternatively, it may be the consequence of inadequate access to health care in which case the emotional and social experience of infertility may be similar or worse when compared to our clinic-based samples. Rural communities in South Africa may be associated with more traditional family structures, and children may play a greater role in daily labour when compared to the urban setting of this research. Answers to these hypotheses require further studies to establish how infertile people who live in other areas of South Africa and who do not seek biomedical help construct and experience infertility.

These limits to the generalisability of our research apply to many related studies in the field, which have similarly focused on clinic-based samples of men and women suffering from infertility. Criticism has been offered to this common approach which relies on convenience samples for testing and which excludes the 5-78% of infertile couples who do not access biomedical care for a variety of reasons (Schmidt and Munster, 1995; Schmidt et al., 1995; Che and Cleland, 2002). It must be considered that people not wishing to be interviewed or not seeking help may differ in their experiences and responses related to infertility (Berg, 1994; Greil, 1997). Recently King (2003) concluded that findings pertaining to psychological distress emanating from research on women attending infertility clinics could indeed be generalised to all subfecund women. This

conclusion was based on an analysis of subfecundity and anxiety in a representative sample of American women suffering from couple infertility, which demonstrated that biomedical treatment-seeking had no moderating effect. Whether this finding applies to other countries in fact remains to be demonstrated.

The common aim inherent in all our studies was to develop an understanding of the patients' perspectives of involuntary childlessness in order to improve their biomedical management. The recruitment of informants from different cultural backgrounds may make it tempting to analyse differences between the various cultural or religious groups. At the beginning of the research a conscious decision was taken to avoid this approach. The research in this dissertation therefore does not offer information as to whether black African women, for example, differ in their social experiences secondary to infertility when compared to women of mixed ancestry. In a country that strives towards integration of culturally diverse communities, any research which highlights cultural differences and which may place people into certain 'cultural categories' has to be very carefully considered. This dissertation aimed to describe the range and depth of constructs and experiences associated with involuntary childlessness across our heterogeneous study population, rather than analysing ethnic group differences. The findings should therefore contribute to formulating interventions which are sensitive and flexible enough to accommodate all groups of men and women from our community. Given the political history of South Africa, this is of particular importance.

The medical background of the principal investigator represents a possible weakness in this research to the extent that the qualitative studies may be lacking certain advanced skills of social scientists who have extensive training and experience in the conduct of qualitative studies. Three strategies were employed to address this potential weakness. Firstly, the principal investigator undertook a detailed review of related original studies in the field (see chapter 1.2) and of published work addressing qualitative research methods. Furthermore, research methods and data analyses were kept purposefully simple. Lastly, collaboration was sought, especially in the initial phases of the research, with other health scientists who were experienced in qualitative research methods.

The medical background of the research team is, however, also a strength of the research, as it assured in-depth knowledge of the biomedical aspects of infertility, infertility management, and of the health system. In addition, it facilitated the integration of our research findings into the health sciences (rather than the social sciences) by virtue of this dissertation, through conference presentations, publications, and the teaching of under- and post-graduate medical students. Although in principle the knowledge basis of two different academic disciplines such as health sciences and social sciences are accessible to each other, in reality differences in thinking, professional terms, reference bases, and search engines for publications (i.e. Medline) may be prominent barriers in this regard.

Integrating an understanding of how men and women construct and experience infertility into the health sciences is particularly important in the developing world where this understanding is often lacking or incomplete. The low-resource setting of developing countries also does not allow for the recommended involvement of qualified counsellors in the management of the infertile couple (National Collaborating Centre for Women's and Children's Health, 2004). As a consequence, patients rely on the knowledge, skills, and understanding of nurses and doctors without the additional input from people who hold professional counselling qualifications.

CHAPTER 3

REPRODUCTIVE HEALTH KNOWLEDGE, HEALTH-SEEKING BEHAVIOUR AND EXPERIENCES RELATED TO INVOLUNTARY CHILDLESSNESS AMONG WOMEN SUFFERING FROM COUPLE INFERTILITY

3.1 INTRODUCTION

Available evidence indicates that involuntary childlessness is a common reproductive health problem in Africa which is often associated with considerable human suffering. This evidence, as derived from an in-depth review of peer-reviewed publications from African countries, has been presented in chapter 1.2. Although the review has identified a considerable number of studies, many questions on the context of infertility and infertility-related health care remain unanswered. In particular, few studies have explored the psychosocial context of infertility in South Africa.

In many African countries, and in parts of South Africa, the problem of infertility is compounded by a lack of appropriate health care facilities. This is not the case for patients living in the Cape Town metropole who have access to tertiary level infertility care within a public health system. Audit at our infertility clinic demonstrated that although the demand for treatment was high, facilities were often ineffectively utilised due to patient drop-out. This raised questions about the reasons for patient non-compliance as well as the need to devise strategies to improve delivery of care.

This study was undertaken in order to gain insight into the understanding that women, who accessed our service, had about fertility and infertility, to explore their experiences related to the inability to conceive, and to assess their health-seeking behaviour. It was

anticipated that the study would identify possible barriers to treatment and offer relevant information which would inform clinical management and counselling programs for infertile men and women living in our socially disadvantaged and culturally diverse communities.

3.2. METHODS

The study population consisted of thirty women presenting to the infertility clinic at Groote Schuur Hospital. All participants were recruited at the time of their first clinic appointment. In order to ensure a study sample which broadly represented the population served by this clinic, informants were selected from four groups of women: Twelve 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 with medical insurance or a monthly family income above a certain level) and paid a higher fee for the services received when compared to 'non-private' patients. Analysing differences between the four population groups was not an aim of the study.

Qualitative methods using semi-structured in-depth interviews were employed as outlined in Chapter 2. An interview guide was developed and the following themes were explored: knowledge of fertility and causes of infertility, health seeking practices, expectations related to infertility treatment, and social experiences related to the inability to conceive (see Appendix A). All interviews were conducted by a single professional nurse prior to the patient meeting with the medical and nursing staff at the infertility clinic.

Operationally defined verbal counting is applied in the presentation of the results as follows: The term 'few' refers to more than one but less than six participants. The words 'some' and 'several' is used for groups of six to 15 informants, with 'some' referring to the lower numbers and 'several' to the upper numbers within this range. 'Many' denotes

a group of 16 to 21 participants, while the terms ‘most’ and ‘the majority’ are used synonymously if a particular theme or finding applies to 22 women or more.

3.3. RESULTS

3.3.1. Demographic Information

Women had a mean age of 31.5 years (range 21-41 yrs) and a mean duration of infertility of 4.8 years (range 1-15 yrs). Twenty-five participants were married. Two informants were engaged to be married, and three women said they could only get married once they conceived.

Twelve women presented with primary infertility. Of the 18 women with secondary infertility, six women had no live child, nine had a child from a previous relationship, and only three participants had a child in their current relationship. None of the informants had more than one live child.

3.3.2. Knowledge of Fertility

Women attributed conception to the act of intercourse. Some women stated that they had no further knowledge. 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 referred to “seeds”, “sperms”, and “eggs and sperms” mixing.

Many women felt their knowledge was limited, and some participants indicated their wish to know more. “I am not clear”, “I do not know very well what happens”, and “I know it only vaguely” were frequent comments. Only two women made some reference to the Fallopian tubes as the site of fertilisation and a passage through which the egg moves. None of the participants could give a simple summary of the biological events leading to conception. A few women felt shy and embarrassed by the topic.

3.3.3. Knowledge of Causes of Infertility

Approximately half of the informants said they did not know what might cause infertility. Despite stating their lack of knowledge most women attempted to explain their inability to conceive. Common explanations included “blocked tubes”, “weak sperm”, and menstrual abnormalities. Although these explanations appeared to reflect biomedical causes of infertility, it was evident that women had developed their own interpretations of these causes. Evidence for the discrepancy between biomedical explanations and patients’ constructs can be found in the following two interview extracts: “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”. And: “When he (husband) was a child, when he was three 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 latter narrative refers, probably, to a clinical diagnosis of undescended testis. For the patient a minor fall was interpreted as the cause of infertility. According to the informant, her mother-in-law was still feeling guilty for not preventing her son’s accident.

Women presented a wide range of other possible explanations, which were not linked to any medically recognised causes of infertility. Two women indicated that evil spirits and witchcraft could cause childlessness. Some women were concerned about a “dirty womb”. These women came in the hope that they would be “cleaned”, either through medication or a “womb scrape” (uterine curettage). A few informants attributed tubal blockage to the previous use of hormonal contraception. Sexual techniques, coincidental medical conditions (such as epilepsy), alcohol abuse, and religious reasons were offered as other possible explanations. “Maybe I am being punished for having sex before marriage” one woman said. Another informant 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.

3.3.4. Access to Health Care

All women had actively tried to access medical treatment after a varying period of infertility. For seven women this period was very long, ranging from five to nine years. One of these women did not know where to access help, one couple was worried about financial implications, and in one couple the husband had refused investigations. The remaining four informants were “just waiting” or did not feel ready for treatment.

In most instances women appeared to have taken the initiative to seek care, although several husbands had “come along” to the doctor. Women had sought medical help from their local clinics or “private doctors” (general practitioners and, at times, gynaecologists). Only few informants had tried to inform themselves and had then arranged to be referred to doctors who were said to have special expertise.

All private patients and one non-private patient had previously accessed specialist infertility care in the private health sector. The reasons why these women now attended our clinic included disappointment with the previous treatment, treatment failure, the successful treatment of a friend or relative at our institution, and financial constraints.

Some informants were referred after appropriate management by a private general practitioner or a primary health care worker. Many other women had, however, experienced barriers, the most common one being ineffective primary care. Although inappropriate care and delays in referral appeared to be a particular problem in the public health sector, it was also encountered in private care. Some women reported to have been given tablets to “clean” the womb. Others had been informed that nothing was “wrong” and that pregnancy would occur “naturally”. A few 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?”

Most women persisted - often over several years - in their attempt to get help by going to “other doctors” and looking for “other advice”. One woman, after going to doctors for ten years without a diagnosis being established, went to a traditional healer as she thought that an evil spirit was hiding the problem from the doctors. Only two women said that there was a time in their help-seeking when they “just gave up” and “had enough”. Both women, however, took the initiative a few years later and were referred to our clinic.

3.3.5. Traditional Health Care

Although only two women had referred to traditional beliefs as possible causes of infertility, six respondents (five black women and one coloured woman) reported that they had consulted traditional healers. These women had received “herbs” or “medicine” to drink in order to be “cleaned”. Two of them 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 follow the calling 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.

3.3.6. Women’s Expectations of the Infertility Service

All women were asked what expectations they had of the infertility clinic. Answers to these questions centred around three issues: The hope to conceive, the hope to receive information, and uncertainty - that is not knowing what to expect.

Approximately a third of the women expressed high expectations of success. These women were confident that the clinic would be able to resolve their infertility. They expressed feeling “curious” and “excited”. Some of the expectations were unrealistic as more than one informant expressed her hope to leave the clinic pregnant after the first visit. The following interview extract reflects this hope and excitement: “Early this morning, I told my mother I am going now. I will get a baby, pray for me. My child said I

must wake up and go now. I said [that] if I don't come back she must know that the doctors are going to give mommy a baby".

Several informants said they did not know what to expect. Some women had doubts as to whether the clinic would be able or willing to help them. These women often appeared anxious. "I was worried, anxious what will be done to me?" one informant said. For a few couples uncertainty seemed to create a barrier as in the following instance: "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".

Ten women came in order to obtain information. These women were worried about their lack of knowledge, of not knowing if, when, and how they could conceive. One informant asked: "Will the doctor answer all my questions?" Another woman emphasised: "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".

The majority of participants were uninformed about infertility management. Many women emphasised 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. Five women wanted to be "cleaned" and one informant hoped that her husband would receive medication to make the sperm "stronger". A few participants had obtained information from the media or friends, but this knowledge was mostly incomplete and distorted. The following descriptions, probably, relate to artificial insemination with donor sperm, artificial insemination with husband's sperm and in vitro fertilisation:

"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 [sperm]".

"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.”

3.3.7. Motivation for Treatment

The majority of informants appeared highly motivated for treatment. Despite not knowing what treatment would entail, women indicated that they were prepared to “do anything”. For some women this commitment appeared to be unconditional. These women were willing to undergo treatment for any length of time and cover costs without question, like the following informant who said: “I will do anything. No matter how much it will cost. I will do everything in my power”. Some women raised 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 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”.

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 time or pay a lot of money she would rather stay without a baby. This woman had a healthy son in her current union.

3.3.8. Emotional Reactions to Infertility

All women verbalised intense emotions when talking about their childlessness. “Burning pain”, anger, deep sadness, bitterness, guilt, loneliness, and desperation were feelings frequently described. Seven 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 several relationships breaking up because of her inability to conceive.

Women explained that "wanting a child was their only wish". 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 the wish to give love to a child.

3.3.9. Effects on the Marital Relationship

Many women described their husband as being supportive and understanding. They trusted their partners and saw them as their friend, often as their only friend. This group included three women who questioned their husband's faithfulness. A few others were concerned that a currently 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" one woman said.

For several participants, however, infertility seemed to pose a serious threat to their relationship. One of these women said that her husband kept threatening her with divorce. Another participant feared that her husband would take a second wife. She explained that, according to 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. Several informants expressed their concerns about extra-marital relationships, and five participants reported that their partners had fathered children out of union.

These women appeared largely defenseless against the threats to their relationship. They did not seem to question the notion that bearing children was a primary function of a woman. One informant explained: "I cannot be anybody in the world if I cannot bear children. He will look for another woman who can bear children". Another woman said: "Then my husband started having children outside our marriage. ... I even went with him to go visit all his children".

One woman thought of ending the relationship herself, 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”.

Although women seemed to carry the main burden of the marital implications of infertility one woman indicated that men could also suffer consequences. “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” she said.

3.3.10. Stigmatisation and Abuse

For many women infertility had considerable implications beyond its impact on the marital relationship. Several women felt cursed, victimised, and ostracised within their own family. Some participants explained that infertility caused disharmony in the family, and three women had avoided marriage because of this. “You and your husband may understand but his family will not. They expect you to fit in. Once you are married and you do not get a child they pass a lot of remarks so that you feel hurt” one of them explained.

Others felt stigmatised and ridiculed in the community. “You see, back home [rural setting] ... 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” another one said.

“Idlolo” (barren) and “stjoekoe” (failure) were words commonly used to scorn an infertile woman. Although some women were able to ignore such negative comments, it caused feelings of pain, sadness, and anger in others. “Stjoekoe, they throw it at me... I feel (like) junk. That is why I don’t have no friends” one informant explained.

Four women reported having been accused of using contraception or terminating pregnancies as unwanted. “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 own mother. Another participant was crying when she repeated what her sister-in-law had said: “She wants to be educated, but she does not want to give my brother a child”.

Four women spoke about physical abuse. This was always from an intimate partner and had mostly occurred in a previous relationship. Three 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 born out by the following report: “He just started slapping me around, beating me. We rented [accommodation] from people, but they would never hear me... I would never make a sound. I do not want people to know what is happening in my life.”

3.3.11. Social Pressure

Several women who did not feel ostracised or verbally abused still felt very pressurised to conceive. 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 her in-laws were almost watching her menstrual cycle. Women experienced this pressure particularly at family gatherings and felt reminded, both intentionally and unintentionally, of their different status. “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 related similar feelings: “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.”

3.3.12. Support and Secrecy

Women were not directly asked about their support structures. However, as women related their experiences with involuntary infertility, sources of support and ways of

coping became apparent. Many women indicated that they received support from their husbands, but the shared burden of infertility created barriers for others who avoided discussing the topic.

Some 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 a further important source of support for 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, for a few women religion was not so much a source of support but the cause of their problem, as they felt that God had punished them with infertility.

A barrier to support appeared to be the secrecy with which some women handled their childlessness. Few informants felt that they could discuss their infertility openly. Others were cautious and selective in the choice of confidants. Not infrequently confidants had similar backgrounds. “My other friend is also having problems conceiving... we share that pain together” a woman said. For a few women this “bond” with another infertile woman created feelings of both support and jealousy. One of them spoke about the “competition” to fall pregnant and how she was praying that her friend would not conceive before her. Later on she cried and felt guilty for these thoughts.

Some women did not want to speak at all to others about their inability to conceive. Sometimes this secrecy reflected a wish for privacy. Many other times it was based on fear, as reflected in the words of this informant: “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” a few 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.”

3.4. DISCUSSION

This study has identified several important factors, which are central to the delivery of effective infertility care. One cardinal factor is the knowledge-base from which patients are operating. Our results demonstrate that women had very little knowledge about the basic principles of human reproduction. Similarly, most women had a poor understanding of possible causes of infertility and were uninformed about modern treatment options. Although many women were aware of their limited knowledge, they did not appear to know how to access relevant information. Where biomedical information had been accessed (through health care providers, relatives, friends or the media), it was commonly transformed and adapted into individual constructs of understanding.

These findings are not in keeping with reports from developed countries which have indicated that women have overall good reproductive health knowledge and easy access to information. Wimberly et al. (2003) explored beliefs about infertility among urban, adolescent African American women in the USA who attended a hospital-based teen clinic. Respondents had a rather sophisticated knowledge of their reproductive anatomy and a good - albeit not necessarily in-depth - understanding of the causes of infertility. Various media together with sexuality education classes were the prime source of women’s information, while health care providers were a less frequently accessed source. In the last decade the internet has become an important source of health information for those who are able to access this technology (Huang et al., 2005; Niederberger, 2005).

According to a questionnaire survey among couples seeking infertility treatment in Canada, nearly half of all respondents had accessed the World Wide Web for information (Huang et al., 2003). In addition to the publicly accessible information, many infertility units in the developed world provide detailed health care information through pamphlets, booklets, posters, and videos to their patients. While this information is likely to be of considerable benefit to the patient, it is associated with not insignificant cost.

In contrast, the results of our study are in keeping with several reports from other African countries which have been discussed in greater detail in chapter 1.2 (Feldman-Savelsberg, 1994; Gerrits, 1997; Bamba, 1999; Koster-Oyekan, 1999; Geelhoed et al., 2002; Leonard, 2002; Sekkade-Kigundu et al., 2004). These studies from Cameroon, Ghana, Mozambique, Nigeria, Chad and Kenya documented an overall poor understanding of biomedical concepts of fertility and infertility, as well as the partial integration and transformation of biomedical information into traditional knowledge systems. Although our data do not show the extent and depth of traditional knowledge systems described in some of the above studies, it demonstrates the persistence of traditional beliefs in a subgroup of our informants. It is interesting to note that although only two of our informants referred to evil spirits and witchcraft as possible causes of infertility, several more had consulted with traditional healers. It must be considered that our study may not reflect the true extent of traditional knowledge systems in our community, as some informants may have been reluctant to share this information. Although the interviews were conducted by a black, Xhosa-speaking professional nurse who was familiar with traditional healing, her association with modern health care and the fact that the interviews were conducted in a hospital setting may have been a barrier in this regard.

Two earlier studies from South Africa have referred to the presence of traditional beliefs and healing in the context of infertility. According to Freedman (1972) both male and female infertility was recognised among the Bantu¹ and witchcraft was considered a possible cause of non-conception. Similarly, Gumede (1978) reported in a review on obstetrics and traditional health care practices among the Zulu that the inability to

¹ Outdated terminology applied to black Africans during the time of apartheid.

conceive was often attributed to witchcraft and that many women sought help from traditional healers, who removed evil spells and used herbs for the treatment of impotence and non-conception. The insight offered by these reports is, however, limited by the fact that no original data from which these observations were drawn were presented.

Health care workers need to take cognisance of the nature and level of knowledge of their patients and of the discrepancies between biomedical and lay concepts relating to health and disease, as these are likely to influence health seeking practices (Atkinson and Farias, 1995). Lack of information can create many treatment barriers. It may induce anxiety which can deter patients from seeking help. Not knowing where to find effective care may cause treatment delays, and the inability to recognise the standard of care may make patients vulnerable to accept and pay for ineffective interventions. Lack of understanding of the complexities of modern infertility treatment may also create unrealistic treatment expectations and, as a consequence, disappointment in modern health care.

The overall lack of information appears to make women critically dependent on the skills and knowledge of their local health care provider. Unfortunately, several women in our study had received sub-optimal care. This indicates a need for the development of clinical guidelines in order to improve the management of infertile patients at primary level care. Evidence for the effectiveness of such guidelines was provided in a randomised controlled trial in the UK involving 82 general practitioners and 200 infertile couples (Emslie et al., 1993). The authors were able to demonstrate that the use of clinical guidelines was associated with significant improvements in patient management.

An important factor identified in this study was the high level of motivation with which women presented to our clinic. In the light of this finding the lack of compliance with modern infertility management, as experienced in our clinic, has to be viewed with particular concern. Although a high level of motivation does not exclude other patient-related factors for treatment non-compliance, it emphasises the need to evaluate critically the delivery of infertility care within our service. This is addressed in chapter 5.

A central finding of our study was the considerable personal suffering and, at times, serious social consequences experienced by women because of their inability to conceive. Several women spoke about marital instability, abuse, stigmatisation, social pressures, and ostracism. Others were saddened by their childlessness but had not faced any negative social consequences. Male partners were often a source of support, but some participated in the process of abuse and stigmatisation. Intimate partner violence was reported by four women (13.3%). It is likely that not all women disclosed their true experiences as underreporting of abuse is common (Jewkes et al., 2002). Furthermore, the prevalence rate of abuse in this study is lower than which has been reported in two other South African studies (Jewkes et al., 2002; Dunkle et al., 2004). This is discussed in more detail in the following chapter.

For some women the psychological implications and social consequences of involuntary childlessness were compounded by a lack of support. In many instances this lack of support appeared to be rooted in the social disapproval that infertility elicits. Social disapproval may be a powerful motivation for women to keep their ‘problem’ secret by employing strategies which include feigning voluntary childlessness and miscarriages. Secrecy in turn creates barriers to support, and thus a cycle of lack of support, social disapproval, and secrecy may be created. Such a cycle may contribute to a ‘culture of silence’ that has been found to surround female reproductive ill health in studies from Egypt and the Gambia (Zurayk et al., 1995; Walraven et al., 2001). These studies documented a high burden of female reproductive organ disease which many women carried silently with few attempts to seek help. This was attributed to the fact that women were socialised to accept and endure reproductive ill health as part of their lives.

Negative social consequences of infertility have been reported from several African countries including Mozambique, the Gambia, Nigeria, Chad, Cameroon and Ethiopia (Feldman-Savelsberg, 1994; Gerrits, 1997; Sundby, 1997; Tilson and Larsen, 2000; Leonard, 2002; Hollos, 2003). According to these studies, which have been discussed in greater detail in chapter 1.2, infertility is for most women an overwhelmingly negative experience associated with, among others, divorce, abuse, loss of social status, poverty,

and lack of old age support. The common findings of these reports and our study are the experience of stigmatisation, marital instability, and loss of social status secondary to infertility. In contrast to reports from Cameroon, Southern Nigeria and Mozambique, women in our study did not appear to fear poverty or lack of old age security and did not struggle with domestic tasks (Feldman-Savelsberg, 1994; Gerrits, 1997; Hollos, 2003). This difference may be due to the fact that the respondents in this study came from an urban and relatively more affluent community when compared to women in the other studies.

While all women in our study were deeply affected emotionally by their inability to conceive, not all of them had experienced negative social consequences. It is important to discern risk factors associated with negative social experiences, but the design of this study does not allow any conclusions in this regard. Investigations into stigmatisation among childless women in South India suggested that more affluent women, while still exposed to stigma and discrimination, were less harshly treated when compared to women from a poorer socio-economic environment (Riessman, 2000). Riessman attributed these differences to better living conditions which shielded affluent women from the surrounding community, while the crowded domestic settings of poor women made their infertility visible to all. In addition, affluence was associated with better education which gave women the confidence to confront dominant ideologies. These findings are in keeping with a previous study from India (Jindal and Gupta, 1989). The authors explored social problems related to infertility among 200 women attending an infertility clinic in a referral centre of northern India. Approximately one third of respondents were victimised within the husband's family, and 16% reported marital problems. Poor and illiterate women were more likely to experience negative family reactions when compared to women who were educated and economically independent. Further research is required to assess whether education and social class may play a similar role in our communities. It is a preliminary observation from this study that the informants which were classified as 'private' did not differ in their social experiences from the other three sub-groups. This observation has to be interpreted with caution since

analysing differences between the four sub-groups of informants was not an aim of this study.

Collectively our findings demonstrate that infertility treatment must encompass information, health education, and counselling, based on an understanding of the construct of infertility and the experience of involuntary childlessness by women who are to benefit from the intervention. This study contributes to such an understanding. Information and counselling must be accessible to the patients. 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 of the fact that due to the interface between infertility, marriage, and sexual functioning they are operating in a sensitive domain that is considered private in most African and many other cultures (Ankah, 1989; Bamba, 1999).

In a study on adoption and infertility in India Bharadwaj (2003) highlighted the need for most Hindu couples to resolve the problem of infertility in 'discrete silence' (often with the 'secret' help of assisted conception), in order both to maintain the sacrosanct privacy of marriage and to avoid the public stigma of infertility. It follows that in countries where infertility is shrouded by secrecy and stigma, patient support groups operating in the community may enjoy little success unless these issues can be addressed. Lastly the level of functional illiteracy must be recognised. Written information, which is a common communication tool in the industrialised world, may be of limited benefit. In our own community functional illiteracy is high. The fact that low educational levels and literacy rates in Africa, especially among women, create barriers for reproductive health care has been recognised (Bamba, 1999).

Biomedical infertility services also need to take cognisance of alternative treatment facilities. Patients who uphold traditional beliefs are likely to look for interventions by traditional healers as documented in our study. The importance of traditional healers in the management of involuntary childlessness has been highlighted in studies from other

African countries as discussed in chapter 1.2 (Savage, 1992; Gerrits, 1997; Sundby, 1997; Koster-Oyekun, 1999; Leonard, 2002; Hollos, 2003). In keeping with the findings of this study, these publications indicate that traditional and biomedical health care are commonly viewed as complementary rather than opposing treatment options. Greater collaboration between the two health care systems has therefore been recommended (Sundby, 1997; Nelms and Gorski, 2006). This collaboration would facilitate referral of infertile clients to the formal health system, while the spiritual and cultural needs are addressed through alternative care structures.

The findings of this study raised a number of questions which included whether the distress demonstrated in many of the interviews could be measured in quantitative terms and how men experienced and constructed infertility. These questions were explored in two further studies which are presented in chapter 4 and chapter 6.

3.5. SUMMARY

This study explored through qualitative research methods, how women who suffer from couple infertility and who accessed modern health care, experienced and constructed their inability to conceive. Lack of reproductive health knowledge, difficulties in accessing appropriate biomedical health care, existence of traditional beliefs, considerable personal suffering and, at times, serious negative social consequences were key findings of this study.

CHAPTER 4

PSYCHOLOGICAL DISTRESS AMONG WOMEN SUFFERING FROM COUPLE INFERTILITY – A QUANTITATIVE ASSESSMENT

4.1. INTRODUCTION

The results of the previous study (Chapter 3) demonstrated considerable personal suffering and serious social consequences among infertile women who presented to our clinic. It also highlighted the fact that many women had experienced difficulties in accessing appropriate care, had limited reproductive health knowledge relating to fertility and infertility and had, at times, inappropriate expectations of the infertility service.

This study was designed in order to gain a quantitative measure of some of the findings raised in chapter 3. The primary objective was to assess whether women suffering from couple infertility had higher levels of distress when compared to non-infertile controls. Psychological symptom status was measured through a standardised instrument, the Symptom Checklist-90-R (SCL-90-R). Although this instrument has not been formally validated in South Africa, it has been applied in research settings in a wide range of studies all over the world (Derogatis, 1994). Secondary outcome measures included a semi-quantitative and quantitative assessment of expectations related to infertility treatment, accessibility of the infertility clinic, help-seeking practices, and the prevalence of abuse.

There is an ongoing debate on the advantages and disadvantages of qualitative versus quantitative research methods in the assessment of infertility-related psychological distress (Wright et al., 1989; Berg, 1994; Greil, 1997). In a critical review of the literature

Greil (1997) concluded that the degree of psychological distress measured in quantitative studies appears to be less overwhelming than the psychological consequences of infertility, which have been described in qualitative studies. Berg (1994), in a discussion on methodological considerations in the investigation of the psychological sequelae of infertility, emphasised the need for 'a more equal balance and blending of both quantitative and qualitative methodologies'. In keeping with this recommendation it was the aim of this study to expand our understanding of the reality of infertility among women from our local communities and not to enter into the debate of qualitative versus quantitative research methods. Generating quantitative data was considered of particular interest, as there appears to be no previous study measuring psychological distress among infertile women in South Africa or in any other African country.

In contrast to the lack of quantitative data on the psychological sequelae of infertility in African countries, several studies from the industrialised world have evaluated psychological distress among infertile men and women, and in some of these the SCI-90-R was utilised (Berg and Wilson, 1990; Downey and McKinney, 1992; Wischmann et al., 2001; Guz et al., 2003). It was anticipated that a comparison between these latter studies, which were conducted in the USA and in Germany, and the index study would offer valuable insights into similarities and differences in the experience of infertility among women from developed and developing countries. The conclusions which may be derived from this comparison are, however, limited by the differences in research methodologies and in the socio-cultural context between these studies.

4.2. METHODS

The study population comprised 120 women who were recruited at the time of their initial presentation to the Groote Schuur Hospital Infertility clinic (study group). The interviews were conducted by one multilingual professional nurse who was part of our research team.

A two-part questionnaire, which is presented in Appendix B, was administered. The first part of the questionnaire was developed in our unit for the purpose of this study and captured data on socio-demographic characteristics, help-seeking behaviour (duration of help-seeking process and sources accessed for help prior to referral), and experiences related to abuse. Women's expectations of biomedical infertility management were explored by asking informants about the expected nature, duration, and outcome of infertility management. Accessibility of the clinic was evaluated by capturing information on mode of transport and duration of travel to the hospital.

In the second part of the questionnaire psychological distress was measured using the Symptom Checklist-90-R (SCL-90-R). This instrument was developed in the USA and we purchased its use. The SCL-90-R is a 90-item symptom inventory designed to measure current psychological symptom status along the continuum of psychological distress, that is from mild distress to profound psychopathology. The test is intended as a self-report measure, but due to the high rate of functional illiteracy in our community it was administered to all participants by an experienced interviewer. Each item is rated on a five-point Likert scale. The test generates nine primary symptom dimensions (somatisation, obsessive-compulsive, interpersonal sensitivity, depression, anxiety, hostility, phobic anxiety, paranoid ideation and psychoticism) as well as three global indices of distress. These indices are the Global Severity Index (GSI), which reflects both number and intensity of reported symptoms, the Positive Symptom Distress Index

(PSDI), a marker of symptom intensity, and the Positive Symptom Total, which measures symptom breadth.

As in other related instruments and scales, the results of the SCL-90-R are expressed as standard area T scores. In order to obtain area T scores, raw scores are initially generated for each primary symptom dimension and for the three global indices of distress. Raw scores are then converted through a mathematical process into T scores. It is a characteristic of the T score distribution that it has a mean of 50 and a standard deviation of 10. A T score of 70 is two standard deviations above the mean. Higher scores are indicative of higher degrees of psychological distress. Area T scores furthermore correlate with centile equivalents. A T score of 60 places the respondent on the 84th centile of a normative population (SCL-90-R norm group) whilst a T score of 70 has a corresponding centile equivalent of 98 (Derogatis, 1994).

The test mean and standard deviations were generated through a norm group of approximately 1000 men and women who represented a stratified random sample of 'normal, non-patient individuals' living in the United States of America. The majority of individuals in this sample were white (85.5%) and married (96%). Information on social class and religion is not available for this norm group.

In order to improve the validity of our study, a local control group was added. This group consisted of 120 women who presented to family planning clinics. Clinics were selected in order to recruit controls from the same local districts in which the infertile subjects reside. The SCL-90-R was administered together with a brief questionnaire capturing socio-demographic data. Information on health-seeking behaviour, reproductive health knowledge, and abuse was not collected in the control group. The interviews in the control group were conducted by three members of our research group one of whom was the professional nurse involved in the assessment of the study group.

The sample size of the study and the control group was derived from a power analysis. There was, however, a lack of data from which the event rate (i.e. psychological distress

measured through the SCL-90-R) could be estimated in either of our two cohorts. Limited information could be derived from two previous studies which measured psychological distress and depression among elderly people living in a poor, black community in Cape Town through other instruments (Ben-Arie et al., 1987; Gillies et al., 1991). According to these studies 13% - 17% of women and 13% of men showed signs of depression, although much higher levels (44%) were recorded in women who had recently migrated from rural areas and who lived in extreme poverty. For the purpose of this study we hypothesized that 20% of the control group would have measurable levels of distress on one or more of the SCL-90-R sub-scales. Based on the results of the qualitative study, we furthermore postulated that infertile women would be twice as likely to have measurable levels of distress. With α set at 0.05 and β set at 0.20 it was calculated that 91 informants were required in each group to power the study at 80%. Alternatively, 119 participants would be required in each arm to achieve 90% power ($\alpha=0.01$). Based on this analysis a decision was taken to recruit a total of 240 participants in order to accommodate a possible degree of error in the hypothesized event rate.

Informants who experienced high levels of distress and women who reported abuse (study group only) were counselled immediately after the end of the interview and then referred to a social worker or to organisations dealing with domestic abuse.

4.2.1. Statistical Analysis

The socio-demographic variables of the study and the control group were compared with t-test statistics (for numerical variables) and the chi-square test (for categorical variables). Mean T scores were calculated, and the student-t test was employed to assess differences between subjects and local controls.

4.3. RESULTS

4.3.1. Socio-Demographic Characteristics

The socio-demographic characteristics of the study group and the control group are listed in Table 4.1. There was no difference in age between the two cohorts. The different languages and religious denominations were equally represented in both groups. Women in the study cohort had significantly lower levels of education and were less likely to be employed when compared to women in the control group ($p<0.05$).

In the study group 106 women (88.3%) were married either by South African law or through religious and cultural practices. Women in the control group were not asked about their marital status as there was concern that this question might be interpreted as judgmental by informants in non-marital, sexual relationships. As expected, significantly more women in the study group were childless when compared to the control group. Eighty-three women in the study group (69.2%) had no live children, and a further 14 informants (11.6%) were childless in their current relationships.

Table 4.1. Socio-demographic characteristics of study group and control group

	Study Group N = 120		Control Group N = 120		P value
Age (years)					
Mean	29.2		28.0		ns
Range	21 – 40		20 – 40		
Live children	N	%	N	%	< 0.0001
Yes	37	30.8	83	69.2	
No	83	69.2	37	30.8	
Home language	N	%	N	%	ns
Xhosa	39	32.5	42	35.0	
Afrikaans	27	22.5	22	18.4	
English	54	45.0	56	46.6	
Education	N	%	N	%	< 0.0001
1 – 7 years of education	16	13.5	4	3.3	
8 – 12 years of education	94	78.3	68	56.7	
Tertiary education	10	8.3	48	40.0	
Religious affiliation	N	%	N	%	ns
Christian	98	81.6	108	90.0	
Muslim	17	14.2	10	8.3	
No affiliation	5	4.2	2	1.7	
ns = not significant					

4.3.2. Psychological Symptom Status

The mean T scores and their standard deviations (SD) of the nine sub-scales and the three global indices (GSI, PSDI and PST) are summarised in Table 4.2. The mean T scores of both the study and the control group were consistently above 50 (which represents the mean of the SCL-90-R norm group). When compared to the SCL-90-R norm group the mean T scores of the study cohort showed moderate (T score 60 to 65) to moderate-high elevations (T score > 65 and < 70) on all sub-scales and on two of the three global indices

of distress. In contrast, the mean T scores of women in the control group were within one SD of the mean of the SCL-90-R norm group (with the exception of the psychoticism scale) and, according to the instrument, as such not indicative of disordered psychological functioning.

The comparison between the study group and the control group revealed that infertile women had significantly higher T scores on all sub-scales and the three global indices of distress, when compared to women using contraception ($p < 0.05$). The differences in the mean T scores between the study group and the control group remained after controlling for educational levels.

Table 4.2. Mean T scores among study group and control group

SCL-90-R Scales	Study group N = 120	Control group N = 120	P value
Somatisation	61.0 $\pm$ 7.6	54.0 $\pm$ 10.8	< 0.0001
Obsessive Compulsive	62.7 $\pm$ 7.4	58.9 $\pm$ 8.9	< 0.0005
Interpersonal Sensitivity	65.2 $\pm$ 6.9	59.4 $\pm$ 9.0	< 0.0001
Depression	63.6 $\pm$ 5.6	57.6 $\pm$ 9.8	< 0.0001
Anxiety	62.1 $\pm$ 7.9	54.3 $\pm$ 11.3	< 0.0001
Anger – Hostility	66.2 $\pm$ 8.2	56.5 $\pm$ 10.0	< 0.0001
Phobic Anxiety	63.3 $\pm$ 7.4	59.8 $\pm$ 10.0	< 0.005
Paranoid Ideation	65.9 $\pm$ 6.2	59.5 $\pm$ 9.4	< 0.0001
Psychoticism	68.0 $\pm$ 7.1	61.2 $\pm$ 10.0	< 0.0001
Global Severity Index	65.9 $\pm$ 6.0	59.3 $\pm$ 9.5	< 0.0001
PSDI *	59.5 $\pm$ 8.3	56.7 $\pm$ 11.0	< 0.05
Positive Symptom Total	66.0 $\pm$ 6.3	58.5 $\pm$ 8.6	< 0.0001

Values are mean T scores $\pm$ SD

Norm group: mean = 50

* PSDI = Positive Symptom Distress Index

Collectively these data indicate higher levels of psychological distress among infertile women when compared to the control group. Note must be taken of the standard deviations according to which women in both groups scored along the continuum of psychological distress from normal psychological functioning to the extreme end of psychological distress. The wider range of the standard deviations in the control group when compared to the study group indicates greater variability in the scores of non-infertile women.

It must be emphasised that an in-depth psychological analysis and interpretation of the data do not fall within the scope of this study. With this in mind, some further observations are of interest. Infertile women scored the highest mean T score on the psychoticism scale. Although this scale captures schizoid psychosis at its extreme end, the scale also reflects social alienation in its lower ranges. The second highest scores were on the anger-hostility scale (which reflects various feelings related to anger including aggression, irritability and resentment) followed by paranoid ideation and interpersonal sensitivity. The paranoid ideation scale is set to capture paranoid behaviour as a disordered mode of thinking ranging from hostility, suspiciousness and fear of loss of autonomy to delusions and feelings of grandiosity. The interpersonal sensitivity dimension captures feelings of inferiority and inadequacy, and, in the higher scores, negative expectations in interpersonal situations (Berg and Wilson, 1990; Derogatis, 1994). The lowest mean T score was found on the somatisation scale which captures distress arising from perceived bodily dysfunctions. None of the 12 items of this scale captures reproductive system symptoms.

Six questions of the SCL-90-R were considered to be problematic in the context of this study. These questions are listed in Table 4.3. For infertile women the endorsement of the question 'How much were you distressed by the idea that something serious is wrong with your body' could reflect the context of infertility rather than the presence of psychopathology. The five questions on the phobia scale were considered a potential source of bias, as the high prevalence of violence in the communities from which the participants of this study were drawn, make these concerns entirely appropriate and valid.

Following scoring of the complete SCL-90-R, these six questions were therefore subsequently withdrawn and the data re-analysed by recalculating the mean T scores and by utilising the paired t-test for the intra-individual comparison of the original and revised T scores.

Table 4.3. SCL-90-R items resulting in potentially confounding interpretations

Item	Scale
The idea that something serious is wrong with your body	Psychoticism
Feeling afraid of open spaces	Phobia
Feeling afraid to go out of your house alone	Phobia
Feeling afraid to travel on buses, subways or trains	Phobia
Having to avoid certain things, places or activities because they frighten you	Phobia
Feeling nervous when you are left alone	Phobia

The withdrawal of the six questions rendered the phobia scale invalid and led to a significant lowering of the mean T score of the psychoticism scale for subjects and to a lowering of the Positive Symptom Total for both subjects and controls. In contrast, the T scores of the Global Severity Index and the Positive Symptom Distress Index did not change significantly (p value[1]; Table 4.4). Importantly, the difference between subjects and controls observed in the original scores was not influenced by the re-analysis of the data (p value [2]; Table 4.4).

Table 4.4. Comparison between original mean T scores and revised mean T scores among study group and control group

SCL-90-R Scales	Study group N = 120	Control group N = 120	P value [2]
Psychoticism			
Original	68.0 ± 7.1	61.2 ± 10.0	< 0.0001
Revised	66.0 ± 7.9	60.6 ± 10.0	< 0.0001
P value [1]	< 0.0001	ns	
Global Severity Index			
Original	65.9 ± 6.0	59.3 ± 9.5	< 0.0001
Revised	65.7 ± 6.8	59.6 ± 9.46	< 0.0001
P value [1]	ns	ns	
PSDI *			
Original	59.5 ± 8.3	56.7 ± 11.0	< 0.05
Revised	59.6 ± 8.3	56.6 ± 10.9	< 0.05
P value [1]	ns	ns	
Positive Symptom Total			
Original	66.0 ± 6.3	58.5 ± 8.6	< 0.0001
Revised	64.8 ± 5.8	57.6 ± 8.4	< 0.0001
P value [1]	< 0.001	< 0.001	
Values are mean T scores ± SD Norm group: mean = 50 p value [1]: within-group difference between original and revised T scores p value [2]: between-group difference in T scores * PSDI = Positive Symptom Distress Index ns = not significant			

4.3.3. Abuse

Three women declined to answer one or more of the questions relating to abuse. Of the remaining informants 17 (14.5%) said that their intimate partner had used physical violence against them, and this had occurred on more than one occasion in 15 respondents. In 29 (24.8%) women the partner had used verbal and/or emotional abuse,

and 26 women reported such abuse from others, particularly from their in-laws. In total 52 participants (44.4%) affirmed the experience of abuse, and in two thirds of these women (n=35) this involved the intimate partner.

The results of a subgroup analysis of the SCL-90-R profile comparing infertile women suffering from intimate partner abuse (physical, emotional and verbal abuse) to infertile women who had reported no abuse from their partners is demonstrated in Table 4.5. Women in abusive relationships had significantly higher mean T scores on the scales of obsessive-compulsive dimensions, interpersonal sensitivity, depression, anxiety, hostility, and on the Global Severity Index when compared to women in non-abusive relationships.

Table 4.5. Mean T scores among infertile women in abusive and non-abusive relationships

SCL-90-R Scales	Abusive Relationships		
	Yes	No	P value
	N = 35	N = 85	
Somatisation	63.1 ± 8.5	60.2 ± 7.1	ns
Obsessive Compulsive	64.9 ± 7.7	61.8 ± 7.0	< 0.05
Interpersonal Sensitivity	67.2 ± 7.0	64.4 ± 6.6	< 0.05
Depression	65.6 ± 5.3	62.7 ± 5.5	< 0.01
Anxiety	64.8 ± 7.4	61.0 ± 7.9	< 0.05
Anger – Hostility	70.1 ± 5.7	64.6 ± 8.5	< 0.001
Phobic Anxiety	65.0 ± 6.8	62.5 ± 7.6	ns
Paranoid Ideation	67.2 ± 5.5	65.3 ± 6.4	ns
Psychoticism	69.2 ± 7.5	67.5 ± 6.9	ns
Global Severity Index	68.0 ± 6.6	65.0 ± 5.7	< 0.05
PSDI *	61.4 ± 8.5	58.7 ± 8.2	ns
Positive Symptom Total	67.3 ± 7.4	65.4 ± 5.7	ns

Values are mean T scores ± SD Norm group: mean = 50

* PSDI = Positive Symptom Distress Index

ns = not significant

4.3.4. Help-Seeking Process

The time informants had spent on seeking help for their fertility problem and the sources that were accessed prior to referral to our clinic are captured in Table 4.6. The majority of women had sought help for at least two years, and approximately one in four women had done so for more than five years. All women had previously interacted with the biomedical health sector. Additional sources accessed included traditional healers, spiritual healers, and homeopathic doctors (Table 4.6).

Table 4.6. Time period spent on help-seeking process and sources accessed for help prior to referral

	N	%
Time Period *		
< 2 years	20	17.7
2 – 5 years	63	55.7
> 5 years	30	26.6
Sources Accessed **		
Medical Doctor	120	100
Traditional Healer	20	16.6
Spiritual Healer	10	8.3
Homeopathic Doctor	2	1.6

* Seven patients could not state the time period

** Several patients accessed more than one source

4.3.5. Women's Expectations of the Infertility Service

Women's answers to the open-ended question what infertility treatment would entail fell into four categories (Table 4.7). The majority of women did not know what to expect other than being 'checked' and 'treated' as required. Some women said they did not know what would happen at the clinic, and eleven came in the hope to have their blood, their tubes, and/or their uterus 'cleaned'. Only 19 informants anticipated specific interventions which were either in keeping with biomedical or lay concepts of infertility procedures. These included reversal of tubal sterilization (n=4), assisted reproductive

techniques (n=5), ‘opening’ of blocked tubes (n=5), removal of a growth or cyst (n=3) and the ‘balancing of hormones’ (n=2).

The majority of women (90.8%) expected the duration of treatment not to exceed one year, and approximately one in ten informants thought it would take no more than one month (Table 4.7). Eleven women said they did not know whether coming to the clinic would help them conceive. The remaining informants were equally divided between those who considered treatment success to be definite and those who felt it was a possibility.

Table 4.7. Expected nature, duration, and success of infertility treatment

	N	%
Nature of Treatment		
To be ‘checked’ and ‘treated’	70	58.3
Specific interventions	19	15.8
To be ‘cleaned’	11	9.2
No expectation	20	16.7
Duration of Treatment Anticipated		
≤ 1 month	9	7.5
2 – 6 months	49	40.8
6 – 12 months	51	42.5
> 12 months	11	9.2
Success of Treatment		
Definite	54	45
Possible	55	45.8
Don’t know	11	9.2

4.3.6. Clinic Access

None of the participants lived within walking distance of the infertility clinic, and the majority (82.2%) was dependant on public transport. Most patients (87.4%) said that

they could reach the hospital within one hour of travel. Two participants thought that transport to and from the hospital might be problematic, and seven informants were unsure. The other participants felt that they could easily access the clinic even if several visits were required within one week.

4.4. DISCUSSION

This is the first study from an African country in which psychological distress was measured in a cohort of infertile women. The results demonstrated that women suffering from couple infertility had significantly higher levels of distress when compared to women attending family planning clinics for provision of contraception. While this result does not imply that all infertile women had elevated levels of distress, our findings highlight the need for health care strategies which encompass both the pathophysiological aspects of infertility as well as the emotional and social reality of the condition. In the context of these realities infertility is, among others, a disruption of lives, a personal loss, a cultural failing and a stigmatising social handicap (Sandelowski, 1999).

Experience from the industrialised world has demonstrated the importance and benefits of integrating psychosocial care into routine medical practice (Boivin, 2003). Two broad types of psychosocial care have been defined, namely 'patient-centred care' and professional counselling. While the former is the ongoing responsibility of all members of the medical team, the latter is provided by a person trained in mental health care. Patient-centred care should ensure that all patients receive emotional support, understand the context of treatment, cope with the consequences of infertility, and adjust to the diagnosis (Boivin et al., 2001; Boivin and Kentenich, 2002). In addition, some couples will require professional counselling. In our own institution - and probably in many related institutions in developing countries- access to mental health care professionals is severely restricted due to limited resources. This places extra emphasis on the importance of patient-centred care. A pre-requisite for this care is an understanding of the reality of

infertility. The findings of both the current and the previous study (Chapter 3) offer insight as to how this reality is shaped in South Africa.

Women in the study cohort had lower levels of education when compared to the control group, but the difference in psychological distress remained when controlling for educational levels. The importance of education as a determinant of the use of contraception has been recognised in studies from Africa, and this may explain the differences in the level of education between the two cohorts (Bambra, 1999). Alternatively, education may shape the risk for infertility by influencing a woman's ability to negotiate safe sex, to seek medical assistance in case of pelvic infection, and to access good quality health care, but there are currently no reliable data with which to substantiate this assumption.

An important observation derived from this study was the fact that nearly one third of infertile participants reported verbal and/or physical abuse from their partners, and that this group of women experienced higher levels of distress when compared to infertile women in non-abusive relationships. As domestic abuse was not the main outcome measure of this study, women in the control group were not asked about abuse. The results therefore do not provide information as to whether infertile women are at higher risk of abusive relationships than women not currently suffering from involuntary childlessness, but indicate that women who are infertile and subject to domestic abuse are particularly at risk of emotional distress.

Our findings are in keeping with a previous study by Leung et al. (2003) who documented that quality of life scores were reduced in infertile women suffering from intimate partner violence. The study cohort comprised 500 women attending a infertility clinic in Hong Kong. Intimate partner violence was, however, an uncommon event and was reported by only nine women. In contrast, high levels of intimate partner violence were reported in a study from Andrah Pradesh, India, which explored the implications of childlessness in a cohort of 322 women who were identified through a household survey

(Unisa, 1999). Two-thirds of women reported intimate partner abuse and 13% of these attributed this at least in part to their childlessness.

In this study 17 women reported intimate partner violence. This prevalence rate (14.5%) is similar to the findings of the previous study (Chapter 3) in which four women (13.3%) said that an intimate partner had used physical force against them. Other studies from South Africa have reported higher rates of intimate partner violence. In a cross-sectional survey involving over 1000 women from three South African provinces 25 % of participants had a lifetime experience of physical abuse from an intimate partner (Jewkes et al., 2002). In a similar sized study on women attending antenatal clinics in Soweto (a large, low-resource, predominantly black community and former township in Johannesburg), 55% of informants gave a history of physical/sexual partner violence (Dunkle et al., 2004). There are obvious differences in the study cohorts, the settings, and the data collection between these studies and ours which may partly account for the different findings. In addition, the other studies were specifically designed to capture information on violence against women and therefore employed strategies which are known to address the problem of underreporting of intimate partner violence. These included specific training of the interviewers and asking the same informant repeatedly and in different ways about abuse (Jewkes et al., 2002; Dunkle et al., 2004). It is, therefore, likely that these studies give a more accurate reflection of the prevalence of domestic abuse and violence in South Africa.

Violence against women has been recognised as a profound health problem and the underlying causes have been the subject of much research and debate (Heise et al., 1994; Heise et al., 2002; Jewkes et al., 2002). Heise et al. (2002) presented a global overview of gender-based violence. The authors, working within the Program for Appropriate Technology in Health in Washington DC, USA, (an international, non-profit organisation which aims to improve people's health globally), attributed domestic violence to several factors which operate at different levels of the social environment. These factors include, among others, the experience of childhood abuse, witnessing violence in the parental relationship, alcohol abuse, marital conflict, community tolerance of violence, rigid

gender roles, and equating masculinity with male honour and dominance. Several of these factors (childhood abuse, violent parental conflict, marital conflict, alcohol abuse, and male dominance) have been identified as risk factors for domestic violence in South African (Jewkes et al., 2002).

The traditional concepts of masculinity in Africa and the ownership that men commonly take of women and of their reproductive functions would suggest that reproductive failure may be a further risk factor for gender-based violence. Interestingly, the association between domestic abuse and reproductive failure does not appear to have been evaluated in a systematic or structured way, and further research in this area is required.

In addition to the evaluation of psychological distress, our study provided a quantitative measure of aspects of women's health-seeking behaviour, their expectations related to tertiary infertility care, and the geographical accessibility of our clinic. The results indicate that many women in our community struggled to access effective infertility care. Over half of all informants said that they had been seeking help for a period of two to five years, and for one in four women this time extended beyond five years. All women had previous contact with a medical practitioner. This finding was expected, as patients only access tertiary care in the public health sector through appropriate referral from a health care professional or when requiring emergency treatment. In addition, several participants had approached non-biomedical sources for help.

These findings are in keeping with our qualitative study (chapter 3) and indicate that short-comings may exist in the effective referral of infertility patients to appropriate facilities. In addition, the results again draw attention to the fact that patients may seek interventions from traditional healers. Possible benefits of a greater collaboration between the biomedical and traditional health system have been addressed in the previous chapter.

Congruency between the qualitative and quantitative data was found with regard to women's expectations of tertiary infertility care. Participants in both studies had very

limited knowledge about modern infertility management. The importance of education and counselling has been discussed (chapter 3). Limited knowledge was often paralleled by high-level expectations. In the current study about half the informants were highly confident about treatment outcome, and 90% of women did not expect this treatment to take longer than one year. Given the nature of infertility management and the restrictions imposed by the limited resources in the public health sector (which lead to long waiting lists for certain procedures) these expectations are unrealistic. Knowledge and understanding of these expectations is important for health care workers so they can address these issues early in the management process in order to prevent disappointment and treatment non-compliance.

The finding that women did not report transport difficulties when accessing the clinic, despite that fact that the majority had to rely on public facilities, was unexpected. In a study on traditional and modern infertility care in the Gambia, Sundby et al. (1998) reported that difficulties in repeated travelling to the hospital together with financial constraints acted as treatment barriers. This difference in findings is probably due to a better public transport system in Cape Town when compared to other African countries and to rural South Africa. Alternatively, at least some women may have given 'correct answers' under the impression that their reliable and regular clinic attendance was a prerequisite for treatment.

The findings pertinent to psychological distress in this study must be related to other studies in the field. There is no study from South Africa or Africa with which to compare our results, but relevant data exist from studies conducted in the industrialised world. Wischmann et al. (2001) applied the SCL-90-R to infertile couples presenting to a tertiary care institution in Germany. Although women suffering from infertility had significant T score elevations on seven of the nine sub-scales the differences were small. The highest mean values were found on the anxiety scale (mean T score 52.7) followed by somatisation (mean T score 51.9) and depression (mean T score 51.9). The authors concluded that their results favoured a 'de-pathologisation' of patients whilst recognising

that a subgroup of individuals may be sufficiently stressed to warrant professional psychological help.

In a related study in the USA, Berg and Wilson (1990) mailed the SCL-90-R to 104 couples who were recruited through a support organisation for infertile people and through two medical schools in North and South Carolina. All couples suffered from primary infertility and were currently undergoing infertility investigations. The study cohort was skewed towards the white population and the middle to upper socio-economic classes. The results demonstrated T score elevations on three out of the nine sub-scales with no significant differences between men and women. The highest T scores were registered on the interpersonal sensitivity scale followed by depression and psychoticism. The GSI for men was in the upper range of normal, and the GSI of women was mildly elevated.

Subsequent to the initial analysis the researchers withdrew 14 questions which they considered to be potentially confounding in the setting of infertility. Following re-analysis the mean T score of the GSI dropped from 60 to 58 and the prevalence of caseness was reduced from 52% to 44% ("Caseness" refers to the presence of psychiatric disorder and is operationally defined as a T score ≥ 63 of the Global Severity Index or of any two primary dimensions). The authors considered these reductions clinically relevant and concluded that although many participants showed signs of psychological strain, few suffered from psychiatric morbidity. The importance of appropriate instruments for the measurement of infertility-related distress was emphasised.

In another USA study Downey and McKinney (1992) evaluated two cohorts of women which were similar to our study. The study group consisted of 118 infertile women who had not had any previous infertility management. Eighty three women who used contraception served as controls. Both groups of women completed a number of questionnaires including the Brief Symptom Inventory which is an abbreviated form of the SCL-90-R. The authors were unable to demonstrate a difference between subjects and controls on any of the ten sub-scales.

The psychiatric symptom status of Turkish infertile women was investigated by Guz et al. (2003). The study cohort consisted of 50 women with primary infertility and 50 healthy, parous women. The SCL-90-R was administered as one of four psychological instruments. In addition, infertile women were asked to describe the reactions of their social environment to their inability to conceive. No difference was observed between infertile and parous women on any of the four instruments. Infertile women who reported negative social reactions (n=25) had, however, significantly higher scores on six of the nine primary symptom scales and on the Global Severity Index of the SCL-90-R when compared to infertile women who did not experience such reactions. The authors concluded that Turkish women suffered from negative social reactions secondary to infertility rather than from the problem of infertility *per se*.

While caution needs to be exercised in comparing the different studies, a few issues justify discussion. The concern raised in the above study by Berg and Wilson (1990) that some questions of the SCL-90-R may be potentially confounding appears justified. We followed a similar approach of 're-scoring' but were interested to find that this did not substantially influence our results.

The recommendation made by Wischmann et al. (2001) in the German study to 'de-pathologise' the psychosocial reactions to infertility seems to have merit. The prevalence of "caseness" was therefore not assessed in the current study. In this context it is important to remain focused on the underlying research questions. The aim of this study was to measure psychological distress as part of the social experience of infertility and not to assess whether infertile women have individual traits indicative of psychopathology.

The most important difference between our study and other publications appears to be a greater magnitude of distress among infertile women in South Africa compared with patients from the developed world. This distress seems to be greater both in width (number of scales showing T score elevations) and depth (degree of T score elevations). It is likely that this distress reflects the profound negative impact that involuntary

childlessness has on the emotional, social, cultural, and economic realities of women in our community. The current findings therefore underpin some of the results presented in chapter 3. They are also in keeping with several qualitative reports from Nigeria, Mozambique, the Gambia and Cameroon which indicate that involuntary childlessness is usually a distressing experience and associated with marital instability, divorce, abandonment, stigmatization, ostracism, and abuse (Feldman-Savelsberg, 1994; Gerrits, 1997; Sundby, 1997; Ezumah, 2003; Hollos, 2003; Umezulike and Efetie, 2004). These studies have been presented in chapter 1.2. The important contribution of this study was to demonstrate that the distress that infertile women suffered can be measured in quantitative terms, and that it was significantly higher when compared to women currently not wishing to conceive and arguably higher than the levels of distress experienced by infertile women in the developed world. These findings help to corroborate the experience of involuntary childlessness in the developing world, an experience which is common and which, by the very nature of its psychosocial implications, is anything but benign.

There are numerous other studies and standardised instruments which have aimed to measure psychosocial distress among men and women suffering from infertility. The results of these studies have been the subject of two reviews. Brkovich and Fisher (1998) concluded that 40 years of research had provided conflicting evidence as to whether infertile people differed in their psychological functioning when compared to the non-infertile population. Greil (1997), in contrast, concluded from a large number of cross-sectional and longitudinal studies, of which all but five were conducted in North America, the United Kingdom or Australia, that infertile people suffered from altered self-esteem and increased levels of distress but not from psychopathology. This conclusion was accompanied by criticism of the existing research which included the lack of data pertaining to people of colour and of low socio-economic classes, and the concern that the instruments utilised may lack both sensitivity and specificity when applied to the problem of infertility. The latter concern has been shared by others, and a number of researchers have attempted to develop more suitable instruments (Berg, 1994; Newton et al., 1999; Glover et al., 1999a; Franco et al., 2002). These instruments have been piloted

in different study cohorts in the UK, Canada and Brazil but are awaiting acceptance and validation on a wider scale.

The finding that the mean T scores of women in the control group fell consistently between the mean T scores of the study group and those of the SCL-90-R norm group highlights the importance of the control group in the evaluation of the results. Rather than interpreting absolute elevations of T scores, attention was given to the observed differences between the two cohorts. It is possible that the raised T scores in the control group are indicative of higher levels of psychological distress among women from low-resourced communities when compared to people in the industrialised world (SCL-90-R norm group). Alternatively, this finding may be due to socio-cultural factors independent of psychological distress.

The fact that the SCL-90-R has not been formally validated in South Africa is a possible limitation of this study. The same is true for many other standardised instruments. The complexity of validation and the limited resources in developing countries are prominent barriers in this regard. The SCL-90-R has, however, been translated into over 20 foreign languages. Though not always formally validated, the instrument has been used in many diverse research settings including studies on the Pacific Islands and among Korean and Vietnamese immigrants in North America (Derogatis, 1994).

The studies described in this and in the previous chapter (Chapter 3) demonstrated that for many women the inability to conceive was a very distressing experience. Women appeared highly motivated to engage in biomedical care but lacked insight into the complexities of modern infertility management. How women experienced the infertility service which they had accessed, and why many of them defaulted from a process they seemed highly desirous of is explored in the following chapter.

4.5. SUMMARY

In this study a standardised instrument, the SCL-90-R, was utilised to measure psychological distress in infertile and non-infertile women. Women suffering from couple infertility experienced significantly higher levels of distress on all scales of the instrument when compared to women currently using contraception. Many infertile women in this study had experienced abuse, and women with abusive male partners were identified as being particularly distressed. In addition, the study provided quantitative information on aspects of women's health-seeking behaviour and their expectations related to biomedical infertility treatment

CHAPTER 5

PATIENT SATISFACTION WITH THE DIAGNOSTIC PHASE OF INFERTILITY MANAGEMENT AND REASONS FOR NON- COMPLIANCE

5.1 INTRODUCTION

The studies described in the previous chapters demonstrated that for many women infertility is associated with emotional distress, negative social consequences, and considerable suffering. In addition, it was shown that women who accessed our service were highly motivated to engage in the process of infertility management, despite often insufficient understanding of what this entails. These findings question the results of the audit, which preceded the research presented in this dissertation, and which, as outlined in the foreword, had demonstrated that many couples who accessed our services defaulted from treatment.

The high rate of patient non-compliance with infertility management is concerning for several reasons. Most importantly, it perpetuates reproductive ill-health in our communities, and in addition it wastes scarce health resources. Treatment non-compliance may also be a reflection of the sub-optimal functioning of a health care system (Hall and Dornan, 1988a).

Foster (1987) reviewed health-care related behavioural research conducted by the World Health Organisation. The author warned against the common approach of attributing poor utilisation of health services in developing countries to 'apathy, ignorance, or lack of concern for health on the part of the patient'. Instead, he challenged health care programs

to question the ways in which they seek to improve the health of people and to recognise that health services are as much of a ‘stumbling block’ to health care as the health-seeking behaviour of the people.

It was the aim of this study to explore health care-related barriers to infertility management in a tertiary care setting and to assess reasons for non-compliance. Infertility management usually comprises different phases, starting with the initial diagnostic work-up, followed by more specific investigations and then interventions, which in turn may involve first, second, and third line treatment options. Some health service-related treatment barriers are likely to affect patients in all phases of management, while others may impact on specific stages of care. This study focused on the phase of the initial diagnostic assessment. The clinical process of this phase has been described in chapter 2.2.1 and includes the first consultation, followed by routine infertility investigations, and a repeat consultation.

In-depth interviews were conducted with female respondents who had successfully completed the first phase, as well as with women who had defaulted from the infertility clinic during this period. We anticipated that this study would offer important insights into the patients’ perspective of tertiary level infertility care and allow us to address possible short-comings and barriers to treatment in our service. Any intervention that increases patient adherence would make an important contribution to the optimal use of the limited reproductive health resources for infertility within the public health sector in South Africa.

5.2. METHODS

Interviews were conducted with 15 compliant and 15 non-compliant women. Participants were recruited from the same study cohort presented in chapter 4 (i.e. infertile women who completed the SCL-90-R at the time of their first visit to the clinic). At the time of recruitment to the previous study (chapter 4), informants were asked whether they were

willing to participate in a follow-up study in which clinic-related experiences and treatment satisfaction would be assessed in a sub-group of randomly selected women. All the women agreed. Patients were not given further details about this study then and were advised that informed consent would be obtained at a later stage from the participants.

In order to diagnose compliance with the initial diagnostic work-up and to establish the background default rate, the progress of these 120 women and their male partners was monitored through the first phase of infertility management. Patients who fulfilled one of the following two criteria were assessed as non-compliant: (1) failure to attend for the routine infertility investigations (semen analysis, mid-luteal phase serum progesterone measurement, infectious disease screening) within three months of the first consultation, and (2) failure to attend for the second consultation at the appointed date or within three months thereafter. These criteria for non-compliance were based on the assumption that these time periods would give the couple sufficient time to attend for their investigations and to re-schedule any missed appointment.

From each group in the cohort (compliant and non-compliant patients) 15 couples were randomly selected by drawing labels from a bag containing the names of each couple in the group. The female partners of these couples were invited to participate in this study. If, despite repeated efforts, the woman could not be contacted or if she refused to be interviewed, additional names were randomly selected until 30 women (15 compliant and 15 non-compliant) were successfully recruited. It was not the aim of this study to assess whether socio-demographic factors were associated with treatment non-compliance, and no comparison to this effect was made between the two groups of informants.

Semi-structured, in-depth interviews were conducted as described in chapter 2 by two professional nurses who were not members of the clinic staff. Respondents were reimbursed for the cost of travel to the hospital. An open-ended interview guide was developed, and themes included clinic-related experiences and difficulties, understanding of information and instructions rendered by the clinic team, satisfaction with the clinical

management, reasons for non-compliance, and suggestions for improvement of the service (see Appendix C). Interview data were processed and analysed as outlined in chapter 2. Verbal counting was operationally defined as in the study described in chapter 3. This definition of terms applies only to the entire cohort of 30 informants and not to any sub-group of respondents.

Informants who had defaulted from the clinic, but who subsequently decided to continue with the management process, were given follow-up appointments at the end of the interview.

5.3. RESULTS

5.3.1. Presentation of Findings

Data analysis demonstrated that women who had defaulted did not appear to differ in their overall experiences related to the clinic or their degree of satisfaction with the management process, when compared to women who had been compliant. The findings pertaining to the various themes identified in the data are therefore presented jointly for compliant and non-compliant respondents, while the reasons for non-compliance are specifically addressed.

5.3.2. Rate of Compliance and Demographic Information

Of the 120 patients monitored for compliance, 45 patients (37.5%) did not complete the initial phase of the diagnostic assessment. The remaining 75 women were compliant according to the criteria applied. Eight women (three compliant, five non-compliant) who had been selected for study participation could not be recruited due to the inability to contact the patient (n=6) and patient refusal (n=2).

Study participants had a mean age of 30.4 years (range 22 – 40 years) and had suffered from infertility for an average of 4.8 years (range 1-18 years). Ten informants were Xhosa speaking, 13 Afrikaans speaking, and English was the home language of seven women. All but two women were married. Sixteen women had no live child. The remaining informants had either one or two children, but only four of these had a child from their current partner.

5.3.3. The First Clinic Visit

The majority of respondents felt that their first visit to the clinic was an overall positive experience, although a few recalled feeling very nervous. Two women were disappointed. One of them wanted to be seen by a doctor and not by a professional nurse, but she decided to accept the situation. The other woman, aged 40 with a long history of secondary infertility, appeared down-hearted when she recalled that the clinic sister had chided her for not presenting sooner and had advised her to re-consider her wish for another child in view of her age.

Two women were angry. One of them had two children from a previous relationship, as did her husband, and none of the children were staying with the couple. This woman was referred to the social worker in order to assess the couple's resources and the social circumstances of the existing children. The woman did not understand why she was referred, and she was resentful of the process. She did, however, comply and was subsequently seen again at the clinic. The other respondent thought that the questions she was asked about her social circumstances were intrusive and unrelated to her problem of infertility. "Because I came for a child [and] I don't think that my living arrangements were quite her [clinic sister] business" she said. This woman had attended the clinic 4 years ago but had defaulted because of long delays in her management. She also recalled being told that she might have had a child by now if she had been more patient, and she was upset about this.

All informants were asked whether they were given adequate information at their first visit and whether the instructions relating to the initial investigations had been clear and easy to follow. The majority of women said that they understood when and where to present for their investigations, although one of them pointed out: “You have to be very quick. If you’re not listening you gonna miss out. Because they [clinic staff] don’t have time to explain three, four times to you”. Women appeared to have different needs regarding the best way of communication. While one informant said that she was too nervous to listen and therefore appreciated the written information she received, another one threw the papers away without looking at them. Two other women, however, felt that the information and instructions were confusing and difficult to follow.

While the majority of respondents felt well informed about what was going to be done, seven women said they did not understand why the investigations were conducted. Only one of them, however, was critical of this lack of information. The accepting attitude of the other informants is reflected in the words of this woman who said: “I didn’t ask questions. That was my own fault. I didn’t ask... because I thought they knew what they were doing”.

5.3.4. Experiences and Health Care Barriers Related to Further Visits

Six informants had no further contact with the clinic after the first visit for reasons discussed below. The remaining 24 participants expressed different degrees of satisfaction with their subsequent management. Ten women said that they were overall happy and satisfied with their management, and some of them indicated that the staff was friendly and helpful. One woman emphasised how pleased she was with the progress and how she was looking forward to her visits. Another one said: “They take good care of us. I have not seen anything wrong... [during] all my visits I have seen nothing that I could criticise.”

Seven women were more reserved in their assessment and used terms such as “can’t complain”, “could be worse” and “not too bad”. The other seven respondents were overtly critical of the clinic. One of these women was angry about repetitive investigation

(semen analysis). She also resented the fact that her views as to which investigations should be conducted were not being considered. She explained: "I have two kids... I know what my body is like and I just want them to do x-rays [HSG]... [but] nobody would listen to me. We go according to the doctor."

The criticism of the other six women who were dissatisfied all centred on the perceived inefficient management of patients' time. These women were frustrated by long waiting times at the clinic and by long delays between appointments. One woman also expressed her annoyance over missing folders and results. Another woman, who had attended the clinic for several weeks, voiced her frustrations that treatment had not commenced when she said: "We come and then we go... we come and go... if we must go on like this... we will probably never have a baby."

Long periods of waiting at the clinic and between appointments also appeared to shape the clinic-related experiences for several of those respondents, who were overall satisfied with their management. These informants were either tolerant of the situation, or they considered it problematic without feeling that it influenced their overall positive impression of the clinic. A few women explained that the long time period between appointments was difficult, because they were anxious about the results of their investigations. One respondent said that fellow patients complained in the waiting area about delays between appointments and about whole days being wasted in attending the clinic, but she took no note of these complaints because "I know that it's [the service] a benefit for me". Another one said, simply: "You know, there's a lot of people. You just have to be patient, that's all". A few women said that waiting was more difficult for their partners, who were less patient, like this woman who was laughing when she said: "He [husband] don't like to wait so long... sitting and sitting... walking up and down... taking the lift down and coming up again!"

Another difficulty commonly encountered was related to the telephone. Several informants reported that they had been unable to contact the clinic or related facilities, because the telephone was either not answered or "permanently" engaged. The words of

this woman, who tried to arrange a follow-up appointment, reflects this experience. “It was engaged, and I told my husband he must also try. And when he tried he could not get through either. I tried for very long so I told my husband: ‘I will go personally and tell them I can’t get through on the phone’ ”. Others, however, did not experience any difficulties and reported that they could phone the clinic without any problems.

Most women were satisfied with the information that was provided at each follow-up visit. These women felt that they were well informed about what they needed or wanted to know and could ask questions if required. A few women had made friends with other patients at the clinic and found these friendships a valuable source of information. Some women, however, felt that they were given insufficient information in connection with their results and/or further management. One of these women explained: “The doctor doesn’t have enough time to talk to you, then you want to ask the sister, but everything happens so fast, you don’t actually get time to ask... why you must go for certain tests.” One respondent, as already mentioned, was angry about repetitive investigations, the reason for which she did not understand. Another one was concerned and confused about conflicting test results. A few women reported that they felt well informed about the current process, but they wanted to know what future management would entail, like this respondent who said: “I have no idea where I am heading, I have given myself over to the hospital.”

The attitude of the male partner towards infertility management was explored in all interviews. Four women reported difficulties and negative attitudes of their partners. One woman, whose husband threatened her with divorce because of infertility, was able to resolve her domestic problems with the help of a priest. The other three defaulted from the clinic after the first visit (see below). All other respondents described their partners as supportive and as actively involved in the couples’ management at the clinic.

All women were asked about transport difficulties and whether they and/or their partners were able to take time off work to attend the clinic. None of the respondents reported transport problems. Only one woman said that both she and her husband had great

difficulties getting time off work, and another two reported their partners had such problems. A few others indicated that the work situation was problematic but not to the extent that it prevented them from attending. One of them explained: “It’s not a problem, but it can spoil my record... to stay out every month or every two weeks, it could cause some problem. [But] I’m not worried about that, I’m more worried about having a baby.” Only three informants raised financial difficulties as a treatment barrier, and in two of them this was a contributing cause to the patient’s non-compliance.

5.3.5. Reasons for Non-Compliance

The reasons for patient non-compliance are summarised in Table 5.1. As already mentioned, six women defaulted after their first clinic visit. In three cases this was due to problems with the male partner. One of these women had told the clinic sister that her husband was taking illegal recreational drugs and refused to attend the clinic. She was seen by the social worker the same day, and although she appreciated the attention she had received, she did not think that anything would stop her husband’s substance abuse. The other women said their partners refused investigation, one, because he did not believe that his fertility was in question, and the other because of excessive work demands. These three women did not return after being informed that male participation was a prerequisite for infertility management and drug abuse one of the exclusion criteria at our clinic. Two of these women were accepting of this approach, but the third one was very disappointed. She indicated that it was important for her to know “if the problem is lying with me”. This woman was subjected to verbal and physical abuse by her partner, which she attributed, at least in part, to her inability to conceive.

Table 5.1. Reasons for non-compliance with the initial phase of infertility management

Reasons	Non-Compliant Participants N = 15
Prolonged absence from health care facility	4
Male partner refusal	3
Dissatisfaction with rendered care	3
Inadequate follow-up management	2
Missed appointment	1
HIV test	1
Negative staff attitudes	1

One respondent was referred to the social worker following the first interview, because both partners were unemployed. The woman was given a referral letter and was asked to phone the social worker for an appointment. Despite repeated attempts she could not get through on the telephone, and she did not have the resources to travel to the hospital in order to make an appointment. Another woman did not return after she was told, as already mentioned, to reconsider her wish for another child in view of her age. Lastly, one informant defaulted because of HIV screening. She and her husband had undergone pre-test counselling but the couple declined the test and then defaulted follow-up. With the help of her partner this respondent subsequently overcame her fears and requested referral back to the clinic at the end of the interview. None of the other participants related problems in connection with the HIV screening, although one respondent said that she had heard other patients express fears and concerns in this regard. Participants were, however, not probed about their attitudes and experiences related to the HIV test.

The other nine informants continued to attend the clinic for some time before they defaulted for a variety of reasons. A few had left town for an extended period of time thus missing their follow-up appointments. These women intended to contact the clinic for a new appointment in due course. One woman was waiting for her next period in order to

phone the clinic as instructed, but she was menstruating very infrequently. Another woman simply missed her last appointment and did not know what to do next.

Lastly, three women and their partners stopped attending because of dissatisfaction with their management at the clinic. All three respondents considered the long waiting periods unacceptable, and two of these also pointed out that they lacked the finances to pay for repeated visits.

5.3.6. Suggestions for Improvements

At the end of the interview all respondents were encouraged to make suggestions for improvements in the service. The majority said that they did not have any suggestions. The suggestions raised by the others (eight 'compliant' and three 'non-compliant' women) predominantly addressed organisational aspects of the clinic. These women felt that the service could be improved if fewer couples were seen, if each patient were given more time during the consultation, if the waiting periods were reduced, and if more information (both written and verbal) were made available. In addition, one woman suggested that the staff should try and create a warmer and friendlier atmosphere, and another one indicated that patients should be phoned periodically to establish their well-being.

5.4. DISCUSSION

Through qualitative research methods this study explored patients' experiences and satisfaction related to the initial phase of infertility management at our clinic and assessed reasons for non-compliance. Monitoring the larger patient cohort from which the respondents of this study were recruited demonstrated that 37.5% of patients did not complete the initial diagnostic work-up. Lack of information, long waiting times, and difficult telephonic access to the clinic featured as central themes in the interviews. Our findings demonstrated that women who were non-compliant (according to the criteria applied in this study) had similar experiences and attitudes - both positive and negative -

to their management at the clinic, as women who were compliant. Reasons for non-compliance varied and included both patient-related factors (e.g. problems with the male partner and prolonged absence from town) as well as service-related factors (e.g. dissatisfaction with the clinical management and inadequate follow-up arrangements).

Many women spoke about long waiting times during clinic visits and between appointments. This waiting was tolerated by some, a source of annoyance and frustration to others, and, in a few instances, the cause for non-compliance. Note must be taken of this theme and health care workers should make a consistent effort to reduce waiting periods wherever possible and appreciate the stress it may induce in the patient.

It is difficult to access more effective solutions in our clinical environment. The hospital appointment system is centralised for all outpatient clinics and, although reduction in waiting times was one of the reasons for implementing the system, it has not addressed this adequately. At present the system is less effective than previously.

The long waiting periods are also a reflection of a high patient workload against a backdrop of limited resources, as noted by some of our informants. One possible solution to this problem would be to devolve part of the workload to the primary and secondary level of care within our public health system. The importance of utilising all levels of care in the management of the infertile couple has been recognised and guidelines have been developed for the management of infertility across the different levels of care (Hanson and Dumesic, 1998; Royal College of Obstetricians and Gynaecologists (RCOG), 1998; RCOG, 2000; Giwa-Osagie, 2004; Morrison et al., 2001). In a discussion on the role of health care services in the clinical management of infertility, Rowe (1999) reported on a health care model, which was developed in South Africa and in which the role of each level of care is defined. According to this model, management at primary level care involves 'screening' infertile couples through history and clinical examination and referral to the next level of care if indicated - provided both partners are willing to participate in the management process. Level two care should include the basic infertility investigations, including, subject to radiographic facilities, hysterosalpingography, as

well as induction of ovulation with clomiphene citrate under certain circumstances. Level three (tertiary hospital) and level four care (sub-specialist unit) should facilitate the more complex management including laparoscopic surgery and assisted reproductive techniques.

There is considerable merit in this model, as well as room for criticism. The fact that we are not aware of this model working successfully anywhere in South Africa, highlights some of the problems in the delivery of health care in our country and, probably, in many other developing countries. This model does not appear to have sufficiently integrated the relevant role players who are willing and able to take responsibility for implementation. The importance of such role players to the success of clinical guidelines has been recently emphasised by Jankowski (2001) in an editorial addressing the implementation of national infertility guidelines in the United Kingdom. The author noted that guidelines are unlikely to result in improved health care unless all groups and individuals who may influence or effect the desired changes are engaged in the process.

In addition to possible shortcomings in the implementation of the model, the resource limitations, which exist at all levels of care, are likely to be a further barrier. Major demands on scarce resources at primary and secondary two care are made by competing health needs. In this setting infertility care is not easily devolved, and a comprehensive but problem-oriented investigation at tertiary level care may ultimately be more cost-effective, as it may avoid unnecessary and repetitive investigations (Mati, 2004).

Some of the challenges of delivering comprehensive and quality reproductive health services against a backdrop of limited resources were highlighted by Fonn et al. (1998). The authors reviewed maternal health services (predominantly primary and secondary level care facilities) in the Northern region of South Africa. The leading complaint by those who accessed the service was not being treated with respect and dignity. Another common complaint, in keeping with our own findings, was long waiting times at the clinics. Women of low socio-economic status were particularly at risk of poor quality care, as they were unlikely to complain or demand better health care. Many health care

facilities were characterised by poor infrastructure and lack of equipment, supplies, and staff. Health care workers themselves considered the care they delivered to their patients as suboptimal (Fonn et al., 1998).

A discussion of the strategies required to address these problems within our public health system is beyond the scope of this chapter. The need to document the negative impact that infertility has on the lives of men and women, in order to motivate health care planners to give greater attention to the needs of infertile couples, must, however, be reiterated. The research underpinning this dissertation makes a contribution to this documentation in South Africa.

Several informants in this study highlighted the importance that information plays in the management process. The need for health education as part of infertility management has been emphasised in the previous two chapters and further discussion of this theme follows in chapter 6.

The observation that non-compliant women expressed largely similar views and experiences related to their clinical management when compared to compliant respondents was unexpected. Researchers from the United States have suggested that non-compliance with infertility care is closely linked to poor treatment satisfaction (Van der Laan et al., 1998). Our study demonstrated a different finding, namely that some compliant women had reasons to be dissatisfied with their care, while others who defaulted expressed treatment satisfaction. This observation indicates that treatment dissatisfaction accounted only partly for non-compliance in our setting. In addition, our results suggest that patients are often tolerant and accepting of shortcomings in their clinical care. This finding is in keeping with the study by Fonn et al. (1998) who noted that several women who accessed maternal health services had minimal expectations regarding the quality of health care.

Reasons for non-compliance varied in our study. The single commonest cause involved prolonged absence from the central health facility. Approximately one in five respondents

who defaulted did so because of treatment dissatisfaction and a similar number because of the unwillingness of their partner to engage in the treatment process. This finding indicates that male partner refusal may be a relatively prominent barrier to infertility management for women who seek help for the problem of couple infertility. The attitude of men towards infertility treatment is explored further in chapter 6.

Organisational and administrative barriers resulted in the non-compliance of a few patients. These barriers are likely to exist in most health services and should be identified through audit and quality control measures in order to make appropriate changes. It is an important finding of this study that some women were unable to overcome seemingly minor barriers. Lack of empowerment, functional illiteracy, and financial constraints are likely to be contributing factors in this regard.

One woman defaulted because of fear of the HIV test. It is hoped that the fear of HIV testing may gradually lessen in our communities, secondary to health campaigns which have addressed HIV-related stigma and access to anti-retroviral treatment. The issues relating to infertility and HIV are discussed in greater detail in chapters 9 and 10.

No other study from South Africa or other African countries has been identified which evaluated treatment barriers and reasons for non-compliance among women suffering from couple infertility. In contrast, there are several studies from the industrialised world, which have evaluated rates and reasons for treatment non-adherence among infertile couples. In a study from Canada, Malcolm and Cumming (2004) reviewed the hospital records of 550 couples who attended a specialist fertility clinic. The non-compliance rate was 60%. Patients were telephonically contacted in order to ascertain the underlying reasons. The leading causes included 'moved away', 'gave up', and spontaneous conception. In contrast, emotional distress and physician/clinic related factors were uncommon reasons for patient default.

Gleicher et al. (1996) reported that approximately one in three couples attending various treatment centres in Chicago, Illinois, defaulted within a few months following the onset of infertility management. Similar to our study, all couples were followed for six months during which they underwent an initial consultation, infertility investigations, and repeat consultation. Couples who decided to abandon the diagnostic assessment and those who failed to return within three months of a missed appointment were considered non-compliant. The majority of patients who defaulted gave no specific reasons, while a few mentioned miscellaneous causes such as illness, 'moved away', religious objections to treatment, and loss of insurance cover. The authors expressed their concern about the lack of treatment commitment among infertile couples and the resulting ineffective use of health care resources. Suggested interventions included appropriate counselling and treatment 'incentives', the nature of which were not specified.

According to Collins et al. (1993), compliance with infertility treatment is influenced by socio-economic factors. The authors conducted a prospective observational study involving 2198 couples attending infertility clinics at eleven teaching hospitals in Canada. The study cohort was followed for seven years, and during this period 13% of couples were lost to follow-up. Low occupational status and unemployment of the female partner were associated with an increased risk of non-compliance (relative hazard 1.61). These findings suggest that the high background rate of non-compliance in our study could be in part attributable to the low socio-economic background of our patients. As previously stated, no attempt was, however, made in our study to assess the association between socio-demographic characteristics and non-compliance.

In addition to studies evaluating patient non-compliance, several studies from industrialised countries have assessed treatment satisfaction among infertile clients. Sundby et al. (1994) assessed patient satisfaction as part of an evaluation of a structured infertility management plan in Oslo, Norway. Data were collected via mailed questionnaires and 262 couples participated. The majority of respondents were dissatisfied with the emotional support rendered by the clinic staff, and 30%-40% felt that

medical information and communication were inadequate. Women who had conceived were overall more satisfied than those who remained childless.

In a questionnaire survey Souter et al. (1998) evaluated treatment satisfaction among 806 women who attended a wide range of health care facilities in Scotland because of couple infertility. Respondents ranked 'doctors' attitude' and 'provision of information' most highly and 87% were satisfied with the received care. Specific questioning revealed, however, that the majority of respondents would have liked more emotional support and information. In addition, several informants said that investigations took too long (27%), were repetitive (20%), and that the waiting time for results was too long (32%).

A study from North America by Sabourin et al. (1991) provides similar insights. The study cohort comprised 385 couples who attended a large, urban fertility clinic in Montreal, Canada. The majority of participants approved of their management. Approximately 10% were, however, dissatisfied because of long waiting times, lack of information, lack of continuity of care, and too little time allocated to the medical consultation.

Schmidt (1998) and Malin et al. (2001) conducted qualitative studies in Denmark and Finland. According to the results, infertile patients considered respectful and empathetic care, no waiting times, provision of information and a clear plan of management as very important. The experience of infertility management did, however, often differ from this concept of 'optimal care'. In contrast, high levels of treatment satisfaction were reported in a later study from Denmark (Schmidt et al., 2003b). This prospective study, which involved 2250 men and women, assessed various aspects of infertility management, including treatment satisfaction. Data were collected through mailed questionnaires. At 12 months follow-up, respondents reported high degrees of satisfaction with both medical treatment and patient-centred care – the latter despite a lack of professional psychosocial services. This was interpreted as being indicative of the fact that formal psychosocial

services were not a prerequisite for addressing the emotional and social needs of infertile patients. Treatment satisfaction was attributed to a variety of factors which included increased awareness of patient-centred care and the provision of written information about psychosocial aspects of infertility at all participating clinics.

There are differences between our study and these studies from industrialised countries. Male refusal of treatment was a reason for patient withdrawal in our study, but not in the studies of Malcolm and Cumming (2004) or Gleicher et al. (1996). This would suggest that male-related barriers to infertility treatment are more likely to exist in our community compared to industrialised countries. Staff attitudes featured less prominently in our study when compared to other studies addressing treatment satisfaction. Although the respondents were assured of anonymity and the interviews were conducted by professional nurses who were not members of the clinic team, it is possible that our informants may have been reluctant to discuss issues relating to the clinic staff. Studies addressing health care delivery in South Africa have reported that unequal power relations and education gaps exist between patients and health care workers (Fonn et al., 1998; Daniels et al., 2000). It is, therefore, possible that our respondents felt hesitant to 'judge' clinic staff or were afraid to do so.

There are also striking similarities between our study and the reports from industrialised countries. In the different studies, informants valued information, appreciated clear treatment plans, waited at infertility clinics and/or for results, and defaulted because of geographical mobility, treatment dissatisfaction and, at times, for no specific reason. These findings indicate that the reasons why patients are satisfied with infertility treatment in different regions are largely similar and that clinic-related treatment barriers are not unique to the low-resource setting of a developing country. Indeed, a meta-analysis of 221 quantitative studies on treatment satisfaction conducted by researchers from Boston, USA, demonstrated that very similar criteria were associated with satisfaction of medical care *per se* (Hall and Dornan, 1988b). The authors reported that the aspects of care patients were most commonly satisfied with included overall quality

of care, humaneness, and competence. In contrast, information, cost, attention to psychosocial problems, and 'bureaucratic' issues (i.e. waiting times) were the areas patients were least satisfied with. The authors forwarded two possible explanations for this observation. It was considered that patients may have given high ratings to overall quality and technical competence because of an inherent need to believe that they accessed 'good' medical care, or because they felt unable to pass judgement on the technical competence of staff. Alternatively, health care systems may have neglected those aspects of care, which are not directly related to treatment outcomes. These include meeting the cognitive and emotional expectations of patients, the need for affordable health care, and the need to minimise 'irritation and delay'.

No study could be identified which evaluated the impact of psychosocial factors on infertility-related treatment compliance. It is conceivable that women who, for example, suffer from high levels of anxiety or depression may have greater difficulties in successfully negotiating infertility management when compared with infertile women who do not experience psychological distress. Although the informants in this study had previously completed the SCL-90-R, we did not attempt to compare the psychological profile between compliant and non-compliant women. This decision was based on the fact that we did not have two 'clean' patient cohorts for comparison, since some women who were assessed as compliant (according to the criteria employed) subsequently defaulted and some non-compliant women re-entered the service at a later stage. In addition, our study was not powered for this analysis.

The method of collecting random samples of compliant and non-compliant informants utilised in this study may be subject to criticism. Although our method of drawing labels from a bag containing the names of each patient is described for the selection of a random sample on a social sciences research website (Trochim, 2004), more stringent ways of random sampling exist. A computer-generated sequence of random numbers would, for example, have been a superior method in that concealment cannot be thwarted as easily

as when names or numbers are drawn in a “raffle” fashion (Beller et al., 2002). This will be considered for future projects.

The design of our study limits some of the conclusions that can be drawn. The informants of this study were women, and the findings therefore apply to this group of patients. According to Hall and Dornan (1990) men, however, do not differ in their assessment of medical care and satisfaction with treatment when compared to women. The authors’ conclusion was based on a meta-analysis which assessed socio-demographic characteristics as predictors of treatment satisfaction and which failed to demonstrate a gender difference. This would imply that the findings generated by this study may be extrapolated (with due care) to men attending our clinic.

The results of our study relate to the initial diagnostic phase of infertility management only, and further research is required to assess patients’ experiences related to infertility interventions. It is, however, likely that the treatment barriers identified in this study affect patient care during the subsequent phases of infertility management. The concern exists that barriers such as waiting times, cost, and time away from work may be increasingly difficult to overcome with longer clinic attendance. The rate of non-compliance measured in this study may therefore increase if longer periods of infertility management are assessed. At the same time, our results demonstrated that for several respondents non-attendance was of temporary nature, and this inflated the rate of non-compliance. Quantitative studies with longer periods of follow-up are required in order to assess the ‘true’ rate of patient non-adherence.

The research presented here and in chapters 3 and 4 focused only on women. Men’s perspective of infertility must also be explored. This is of particular importance as there are few, if any, existing studies from South Africa or Africa, which offer insight into men’s construct and experiences of infertility. Chapter 6 presents findings from in-depth interviews with male participants who spoke about their experiences related to infertility.

Whether men suffering from couple infertility have elevated levels of psychological distress, and how this distress compares to that of fertile men and to infertile women is discussed in chapter 7.

5.5. SUMMARY

In this study in-depth interviews were conducted with 30 women who accessed our clinic and who had either completed the initial infertility assessment (n=15) or had defaulted from the clinic during this period (n=15). Women in both groups expressed varying degrees of treatment satisfaction. Long waiting times, lack of information, and limited telephonic access to the health service were some of the service-related treatment barriers identified. Staff attitudes did not feature prominently in the interviews. The background rate of non-compliance was 37.5%. Prominent reasons for non-compliance included prolonged absence from town, male partner refusal of treatment, and dissatisfaction with the medical care.

CHAPTER 6

REPRODUCTIVE HEALTH KNOWLEDGE, HEALTH-SEEKING BEHAVIOUR AND EXPERIENCES RELATED TO INVOLUNTARY CHILDLESSNESS OF MEN SUFFERING FROM COUPLE INFERTILITY

6.1 INTRODUCTION

To date most studies exploring the impact of infertility on reproductive health in Africa have focussed on women. This focus is probably based on the understanding that in African countries women carry the main burden of infertility as they appear to be 'blamed', often solely, for a couple's childlessness (Meheus et al., 1986; Savage, 1992; Inhorn, 2003b; Ikechebelu et al., 2003). Few studies have included male participants, and most of these were aimed at assessing the prevalence and aetiology of male infertility (Mbizvo et al., 1984; Osegbe and Amaku, 1985; Mbizvo et al., 1989; Yeboah et al., 1992; Bornman et al., 1994; Ikechebelu et al., 2003). As a result very little is known about men's experiences of involuntary childlessness in Africa (van Zaandvoort et al., 2001).

In this study qualitative research methods were applied in order to explore men's reproductive health knowledge about fertility and infertility, their health-seeking behaviour, and their experiences related to involuntary childlessness. It was anticipated that the results of this study would offer important information about the male perspective of couple infertility and how this compares to that of women. This information is essential in order to understand and respond to the reproductive health needs of couples who present with involuntary childlessness.

6.2. METHODS

Twenty seven men who suffered from couple infertility and who presented with their partner to our clinic participated in this study. Men were recruited at their first clinic visit, prior to interacting with the medical team. In order to ensure that the study population was broadly representative of the local communities accessing our clinic the following informants were selected: twelve coloured or white men, nine Xhosa-speaking black men, and six men from the Muslim community (coloured).

The selection of informants and the size of the study cohort was very similar but not identical to the study described in chapter 3 which involved women presenting with couple infertility. A decision was taken not to include patients with medical insurance or a monthly family income above a certain level who could access private care in this study. This was based on the observation that the six women who were included in the previous study because of their private patient status did not appear to differ in any of the outcome measures when compared to the remainder of the group.

Qualitative research methods were employed as outlined in chapter 2. Two multilingual healthcare workers were involved in the data collection. The interview guide was the same as utilised in the study described in chapter 3 (see Appendix A). The themes included knowledge of human reproduction and of the causes of infertility, expectations of and attitudes towards infertility management, infertility related health-seeking behaviour, as well as emotional and social experiences of childlessness.

The presentation of results contains numerical and operationally defined verbal counting as outlined in chapter 2.4.1. In this study the term ‘few’ refers to more than one but less than five informants. The words ‘some’ and ‘several’ are used for groups of 5-13 participants with ‘some’ referring to the lower numbers and ‘several’ to the upper numbers in this range. If a finding affected between 14 and 19 men the term ‘many’ is applied, while ‘most’ and the ‘majority’ are utilised synonymously to indicate that 20 or

more of the informants were involved in a particular theme or finding. This operationally defined verbal counting only applies to findings involving the entire study cohort.

6.3. RESULTS

A total of 32 men was asked to participate in the study. One man refused on the grounds of having insufficient time for the interview. Thirty one men were interviewed. One interview with a Xhosa speaking participant had to be terminated. This man consented to participate but was subsequently unwilling to discuss any of the issues raised in the interview. A further three interviews (two coloured men and one man from the Muslim community) could not be analysed, as the audio-tape was inaudible because of a technical problem which only became apparent at the time of transcription. According to the field notes these informants had spoken clearly about their experiences and had not raised themes which were new or significantly different from the other interviews. In view of the qualitative nature of this study, these four informants were replaced in order to reach the desired number of interviews (n=27) for data analysis.

6.3.1. Demographic Information

All but three of the informants were married. Fourteen participants had no live child. Of the remaining 13 informants four had one live child in union. The other eight men had one or more live children from a previous relationship.

6.3.2. Knowledge of Fertility

The majority of informants had limited knowledge of the biological process of human reproduction. Six of the informants could offer no information other than that a woman fell pregnant through intercourse. Several participants explained that male and female “sperm” or eggs and sperm had to “meet” or “connect” within the woman's body for conception. Two men said that intercourse caused “cells” or “seeds” to be released inside the woman's body which subsequently grew into a baby. “I have the sperm and she has

what makes my sperm fertile” one of the informants explained. Only one man was able to sum up the basic biological facts referring to ovulation, fertilisation, and implantation.

6.3.3. Knowledge of Causes of Infertility

Men offered a wide range of factors as possible causes of infertility. Biomedical explanations included low sperm count or “weak sperm”, menstrual abnormalities, blocked tubes, and previous use of contraception. A few men referred to sexually transmitted diseases as a possible cause of male infertility as illustrated by this participant who said: “There are men who can be a problem [with regard to fertility], because there are those who cannot have one wife or one girlfriend, and now they start to have diseases and... they make him weak”.

Other causes of infertility included religious considerations (either God's will or God's punishment), life-style (“bad living”, use of drugs, diet and stress), a “dirty womb” as well as witchcraft. The latter would usually be exerted by some jealous person with or without the help of a witchdoctor. Two men felt that their infertility was invoked by ancestors who did not approve of their relationships or who were offended by the couple's nonconformity with traditional rituals.

All but one of the participants were aware of the possibility of male infertility. Five men felt that male infertility might indeed be more common than female infertility. “Women are born to have children” one of these informants offered as explanation. Four of the participants felt that female causes were more common, and the remainder considered the ratio to be equal or were unsure about it. Despite this awareness of possible male infertility a few informants felt that most men would blame their partner, because they did not like to admit that they had “the problem”. One of the informants gave a reason for this attitude: “In society today... man cannot be the problem. He has got this stereotype... he is the man and nothing could be wrong with him”. Some men, although aware of male infertility in general, were confident that they were fertile either because they had previously fathered a child, or because they interpreted the ability to ejaculate as proof of their fertility.

Several participants said that they did not know what would prevent a man and a woman from having children, and that they had come to this clinic in order to find out. Two of these informants felt that they lacked knowledge as other men who were childless would not talk about their situation.

When asked about the presumed cause of infertility in the index relationship, eight men said they did not know, eleven informants thought the problem lay with their female partners, four men were concerned about a possible male factor and the remainder considered the possibility of both male and female factors.

6.3.4. Expectations and Concepts of Biomedical Infertility Management

All participants were asked what expectations they had of their first visit to the infertility clinic. Answers were mostly vague and centred around the hope to receive information, the expectation to be “checked” or “tested” and then treated as necessary, and to obtain “help”. The majority of men said they did not know what investigations would be required or what treatment could be offered and emphasised that they had come to the clinic in order to be given this information. The following interview extract illustrates these concepts: “What I expect is that they are going to tell me exactly what the problem is, if I am the problem or if she is the problem, and whatever they can do at this stage”. The importance of information is also reflected in the words of this man who said: “Knowledge of what is wrong is already a great comfort”.

Some of the participants expected to receive medication or to join a “program” in order to make the couple more fertile. “They will first check me and my girlfriend. That will help them discover where the problem is. Then they will know what to mix so as to help us in bearing children” one patient explained. The need to clean the body or bodily parts (i.e. blood or womb) of one or both partners was a concept held by five of the informants one of whom said: “I think they are going to clean my wife, so that she can menstruate, because I think the problem is this blood which she must shed but which is not coming out every month”. One participant felt that infertility management was much more complex than treatment of other conditions. “If you talk about a heart... or somebody

needs a kidney...most people know about dialysis machines. But when it comes to infertility I think it's a lot more difficult to treat. It's not something you can cut out or stitch up and you are better".

A few of the participants referred to biomedical terms and procedures, such as "insemination". It was, however, evident that these men remained very unsure as to what these terms and procedures implied. This uncertainty is reflected in the questions of the following participant: "I really don't know what this treatment will entail. Will there be any operations, or are they going to draw sperm out of my body? How are they going to do that? What are they going to do with my wife? Are they going to implant sperm into her, operate on her?" Only one man appeared to be adequately informed about some principles of infertility management. He and his wife had previously undergone assisted reproductive techniques in the private health sector.

6.3.5. Treatment-Seeking Behaviour

Sixteen informants said that the decision to seek help had been a joint decision between them and their partner. This included a few instances in which the couple had agreed that the woman would go and see a doctor. In the remaining couples the help-seeking initiative was taken either by the woman (n=6) or by the man (n=5). Two of the five men who initiated the treatment process said that their wives were too shy to see a doctor, and one felt that his wife was not as keen as he was to have another child. The presumed underlying cause of infertility did not appear to influence who initiated the health-seeking process.

Most of the informants had accessed the health care system via their general practitioner or the local primary care facility in the public health sector. Couples were then referred to our tertiary care clinic, often at their specific request. A few informants experienced delays with this referral process but only one expressed dissatisfaction. Only three patients had seen a private specialist, and only one couple had previously received infertility treatment (at a private tertiary care facility).

Four black informants had seen a traditional healer, and a further two contemplated doing so. Treatment from traditional healers involved traditional medicine or herbs to “clean the blood”. It was evident that traditional medicine and biomedical health care were viewed as complementary rather than opposing options. This can be seen in the following interview extract referring to the support from family members and friends: “They are supportive because they are even saying that we must consult our ancestors and... do our traditional ceremonies. They give advice about our culture, and they also encourage us to come to the clinic”. One of the couples who felt that their childlessness was invoked by their ancestors had organised family festivities to communicate with the ancestors and had then waited for a year to see if they would conceive.

Most of the informants were highly motivated with regard to investigations and treatment. “Yes, obviously, yes. That's why we are here... to solve our problem. Yes, definitely, yes” one of the informants answered when asked whether he was willing to undergo investigations. Several men expressed an unconditional willingness to do “anything” that was required of them. “I don't care what I have to go through, I will do it” one patient explained. A few others, however, expressed reservations or even resentment. “A man is always reluctant to come to a place like this” one patient explained. And another man asked: “Why must we come [to the clinic]... why can't we have children like normal people?”

All participants were asked specifically about their attitude towards semen analysis. This topic was explored without supplying the participants with information about the procedure. Twenty of the informants said they would be willing to comply. A few men appeared even eager to be tested. “I want to find out if my sperm is fertile or infertile. I want to know” one man emphasised. Four men did not know how a sperm test would be conducted like this man who asked: “I don't have a problem, but I want to know how or where will they get the sperm from? Through injection or from my wife?” Seven participants expressed reservations about producing a sperm sample by masturbation. Three of these considered the procedure embarrassing, and four informants said that masturbation was “not within their culture”. Their concern is reflected in this interview

extract: “I think that [masturbation] will be a little bit difficult. But if it is supposed to be done I'll do it. But why masturbation? Is there no other way?”

6.3.6. *The Wish for a Child*

The reason for wanting a child was not systematically explored in the interviews but was a theme which was raised by many of the informants. Several men expressed their wish and desire for a child in rich words. “A child is like our love being born and walking around” one informant said.

Men outlined a number of reasons for wanting a child, and some gave more than one reason. “I take it that any man wants to give children to his wife” one participant said simply. Ten respondents thought that children would bring love and happiness and would fulfil the marital relationship. “Each relationship is there for the sole purpose of reproducing your kind” one of them said. Another one explained that “a child helps a relationship to be strong, but if there is no child... it becomes easy for that relationship to be destroyed”.

For six men children were important for continuity in life so that they could pass on their material goods and/or their name. One informant emphasised that only a boy could, however, be his successor, although a girl could make a man rich through 'lobola' (bride wealth).

Lastly some men gave reasons relating to social pressure and status. This is summed up in the following interview extract: “Society dictates... [if] you are not married they tell you: ‘When are you getting married?’ When you get married they say: ‘When are you making plans for a child?’ When you have your first child they say: ‘Now you must make another child’... that's how they pressure you. Then... say now you have four children, they say: ‘Hey, this man is like a rabbit’ ”.

6.3.7. Experiences of Infertility

Only three patients said that they did not feel particularly affected by their childlessness. Most of the others were outspoken about the emotions that involuntary childlessness induced in them and feelings of sadness, pain, and emptiness were described. Some men spoke about a deep longing inside and about feeling down, guilty, left out, and heart-broken. "It is hurting, it makes me sad. I don't like it, because it makes me feel inadequate" one informant said.

Eight men also expressed feelings of anger, frustration, and helplessness. One man revealed possible consequences saying: "It feels like I can do anything, maybe hurt somebody or things like that". Some felt that not having children affected a man's identity. "You feel like you are half a man" one patient said. And another one explained: "You see, you are... a man because you have children. But if you don't have children some other guys say you are a woman".

6.3.8. Effects on the Marital Relationship

Many informants said they had a good and loving relationship. Two men had noticed that as time had gone by they learned to deal better with the issue of childlessness in their relationship, and one of them said: "You learn to live with [it]. We love each other, and even though there is this yearning for a child on my side I won't push her away or be angry with her". Some men expressed feelings of sadness for their partner's suffering. "I must be highly supportive of her" one of them emphasised, "when she sees her sister's children I can see that she really thinks about the issue... then I... make a joke just to help her forget about it".

Among the informants who had described their relationship as "good" one man referred to an episode during which he had physically assaulted his wife, and another man admitted to an extra-marital affair. Some of the other respondents felt that their childlessness was a source of arguments, but only four men made negative comments about their marriages which, they said, were taking "strain" or getting "stale". None of

the informants expressed concerns that infertility might threaten the relationship to the degree of causing separation and/or divorce.

When the impact of infertility was approached in general terms, away from the index relationship, several informants felt that childlessness could have very negative effects on a relationship including divorce and domestic violence. A few men acknowledged that women were likely to suffer more under these negative experiences when compared to men. “Maybe they [men] drop her [female partner], they leave her... or maybe some men they drink or they lie and begin hitting her” was the view of one patient. According to another participant a woman’s children from a previous relationship could also become the target of abuse under these circumstances. A third informant described the behaviour of some childless couples. “They go to alcohol, they abuse drugs, there is sleeping around. A man gets tired of his wife, and a wife gets tired of the man and they cannot take it. This happens a lot in [my] area and where I work. It is not nice to see how people throw themselves away if there are no children”.

Some of the informants felt that partners in an infertile relationship might be tempted to test their fertility with other men or women. “Because you are blaming each other, and one might want to go outside to test if it is really him or her” one patient explained. Another man felt that marriage created certain expectations, and if these were not fulfilled it would be “automatic” to look for another woman. These men emphasised that they were speaking in general terms about extra-marital relationships and not about themselves. Only one informant acknowledged to have impregnated another woman just a few weeks prior to coming to the clinic. But as he was a married man and his girl friend a young woman without parents and who was also carrying responsibility for a younger sibling, the pregnancy was terminated.

6.3.9. Experiences in the Family Setting

Men had different experiences with regard to infertility in the setting of their families. Six men said their families were supportive and a source of comfort and advice. One informant explained how his parents and siblings had encouraged them to get help.

“They know... the emptiness in her [partner’s] life and if they [siblings] could they would even give one of their children to us... but... we want a child of our own” he explained. Another patient, who had a child from a previous relationship said: “All the family knows she wants a child... and everyone has sympathy for her, and the sympathy is bubbling out of her ears now”.

Just under half of all the informants, however, felt pressurised by their families. They were uncomfortable about the “questions” that were asked and the jokes that were made. Four men acknowledged that others might be unaware of the impact of their comments. Another man described how others would tease him: “Sometimes... we are together and everyone talks about their child, so they start. They take it as a joke but to me it is not a joke. I do not feel alright that I do not have a child”. In a few instances the reactions of other family members to infertility seemed to be based on perceived violations of social norms. “You know us Xhosa people, as soon as you get married they expect you to have children whether you are ready or not” one informant said. The influence of a different norm is apparent in the words of this patient: “My in-laws... pressurise my wife. And then they tell her: It’s because you had sex before marriage, that’s why”.

6.3.10. Experiences in the Community

Three respondents said that the community did not treat them any differently from men who had children, and a further two informants felt that although jokes would be made, infertility was not a cause of ostracism.

The majority of men, however, reported negative experiences within their communities because of their childlessness. Several informants explained how infertility would induce “talk” in the community. “The community will be talking behind your back, and the wife will be scorned. The family will treat such women badly... because most of the time we grow up believing that women are responsible for this” one man reported. Men, too, according to this informant had “tough times” as “no good words are going to be said about you...they degrade you”. Many participants spoke about the “jokes” that others would make. Men were called names such as “tjoekee” (failure) or “incabi” (castrated

cow), comments would be made about “bad swimmers”, “shooting blanks” and “water penis”, and a man’s worth to society and to his wife might be questioned.

Some informants laughed and said they would just ignore such talk. Several others experienced these “jokes” as hurtful and insulting but felt they had to accept them. “Sometimes maybe you laugh with the joke”, one participant said, “but it’s actually not good...because it breaks you. You are already going through... emotional things and... you exercise patience with your wife and here a guy comes along and just calls you a name”. Another informant described possible follow-on effects. “When men are sitting together... some say jokingly: ‘Bring your wife to me, I can do it for you’. Those words are passed as a joke, but when you are on your own, thinking about all that is being said, you feel insulted. [And] if your wife one day comes home late... those things can come back to you. You think that maybe she thinks I am worth nothing, because I can’t give her a child, maybe she has started seeing somebody else”. This suspicion of her infidelity could lead to domestic violence. “Because the whole thing starts haunting you. You will be wanting somebody to take out your frustration. Unfortunately, your wife will have to take that because you don’t have another way of taking out your anger”.

Lastly some men described how childlessness affected their social status. These participants reported that men without children were not respected, not considered an adult, and not treated as a “man”. “What I have seen is that they do not respect you. You [are] not a man if you cannot bring children into the world” was the experience of one respondent. Another man said: “You know, in our culture if you cannot bear children you are not considered to be a person. They say you are a weak man. During community meetings, when this person has to say his views, other men will say ‘What are you talking about, you know nothing, you don’t have children. Sit, only those men with children can talk’ ”. A few men talked about exclusion from the custom of letting children do certain tasks. “Let us say that an elderly person wants to buy something in a shop, then he requests one child to go shopping for him”, a participant explained. But if a man had no children other parents would not allow this man to send their child but would tell him to make his own. This was perceived to be both a hurtful and insulting experience.

Men appeared to handle these negative experiences in different ways. Several expressed feelings of hurt, anger as well as shame and embarrassment. “They put you on the spot” one participant explained about the “questions” that would be asked, “and you feel you just want to vanish”. And another one said: “If you are a man and the [fertility] problem is on the man’s side... you want to hide, you don’t want to go out in the community”. Eight of the informants explained that they tried to ignore provocations or avoid social contacts like this man who said “If I am going to take note... I will have to report myself to a nuthouse [mental institution]”.

Pretending not to want to have a child was another strategy employed to avoid negative experiences. Others said it was up to each individual to deal with the experience. “Some people will criticise you, but if you are happy with your woman you don’t worry when they criticise”. A few of the men who appeared unaffected by the negative input were concerned about their wives who did take the ‘talk’ seriously and suffered under it.

6.4. DISCUSSION

The results of this study offer new insight into the male perspective of infertility. This perspective encompasses limited reproductive health knowledge, support for the female partner, an overall willingness to be involved in the help-seeking process and, not infrequently, negative emotional and social consequences. These findings should not be interpreted as contradictory to the general concept that women carry the main burden of infertility but be viewed as an addition to our existing understanding of the reproductive health needs of both men and women. This broadening of our understanding is of particular importance, as there are very few publications from sub-Saharan Africa in which the context and construct of infertility among a cohort of men suffering from involuntary childlessness has been explored.

Lack of adequate knowledge was a central finding of our study. Men were poorly informed about basic reproductive biology, causes of infertility, and modern treatment

options. When comparing the results from this study to the information gathered in the study of women's experiences (chapter 3) it becomes evident that men and women had similar knowledge and concepts. Similarly, respondents in both studies were anxious and eager to obtain information.

These findings highlight again the need for health education and counselling. Several studies from the industrialised world have documented the importance infertility patients attach to medical information. Glover et al. (1999b) reported that men who attended a male subfertility clinic in London considered obtaining information one of the most important aspects of the medical consultation. In the Netherlands, van Balen et al. (1997) explored the help-seeking behaviour of 131 infertile couples, who were identified through a household survey. Participants indicated that obtaining medical information and understanding the cause of infertility were prominent reasons for seeking medical care. Similarly, most of the studies which evaluated infertility-related treatment satisfaction, and which have been discussed in chapter 5, highlighted the fact that patients valued information (Sabourin et al., 1991; Souter et al., 1998; Schmidt et al., 2003a).

In Africa, where knowledge about sexuality, infertility, and reproductive health is often inadequate this need for information is even higher (Sundby, 1997; Bambra, 1999; Walraven et al., 2001). Information delivery, based on an understanding of people's concepts of health and disease (Atkinson and Farias, 1995), must form a key aspect of infertility management in the developing world. The need for information is of such importance, both to the individual patient and to the advancement of reproductive health in the community, that information and counselling should be accessible even in the absence of other treatment options.

The overall lack of reproductive health knowledge among the participants was paralleled by the existence of traditional beliefs and health-seeking behaviour. Although not commonly quoted, concepts of witchcraft and ancestral power clearly existed. This result underpins the findings of the two studies described in chapters 3 and 4. Collectively

they indicate that traditional beliefs remain influential in some of our communities, are shared by both men and women, and may influence the health-seeking process.

The observation that producing a semen sample by masturbation was problematic for several of our informants is in keeping with a study by Blenner (1991) which documented that there are cultural and moral barriers to masturbation among African, Oriental, and Mexican men. Except for this possible treatment barrier, most men in this study appeared very willing to engage in the treatment process.

This finding appears to contradict the results of the study described in chapter 5 (which documented negative male attitudes to infertility treatment in our communities) as well as a few studies from other African countries, which have reported many barriers to the involvement of men in infertility management. Anate and Akeredolu (1994) classified men's attitude to infertility management into three categories (good, fair and poor) according to their willingness to undergo investigations and comply with prescribed medication. The study cohort consisted of 108 randomly selected male partners whose wives attended an infertility clinic at the University Hospital in Ilorin, Nigeria. According to the study criteria, only 37% of participants had a good attitude while the others demonstrated fair (25%) or poor (38%) attitudes. Variables associated with poor attitude included polygamy and having live children from previous/other relationships.

Studies from the Gambia documented that the help-seeking process for infertility was usually initiated by women and that husbands rarely accompanied their wives, often refused to be investigated, and were not invited by the health care personnel to attend the clinic (Sundby, 1997; Sundby et al., 1998). Savage (1992) evaluated socio-cultural barriers to artificial insemination by donor (AID) among 102 infertile men and women from the middle to high income group who attended the infertility clinic at the University Hospital Centre in Yaounde, Cameroon. The majority of informants (80%) rejected AID as a treatment option, and 22% considered male polygamy preferable to AID despite that fact that the indication for AID (male infertility) had been clearly explained to the

participants. The author attributed this response to the inherent belief that infertility was always a female problem which could be remedied by taking a mistress or second wife.

Similar attitudes have been reported in a study from Zimbabwe (Folkvord et al., 2005). The authors studied a cohort of 311 men who attended a male infertility clinic in Harare. Although men were informed about the diagnosis of male factor infertility, many continued to blame their wife. This attitude was attributed to the male-dominated culture in Zimbabwe which depicts men as faultless and which make it difficult for infertile men to acknowledge their condition.

The differences in health-seeking behaviour between the index study and other reports from Africa could possibly be attributed to better -- although still limited - educational and health resources in our urban region when compared to rural areas or other African countries. These resources may facilitate a better understanding of reproductive health matters including male factor infertility which, in turn, may have a positive influence on male involvement in the treatment process. Importantly, informants in this study were recruited from a cohort of men who were willing to accompany their spouses to the clinic. It is likely that this influenced the findings regarding knowledge of male infertility and health-seeking behaviour. The results of the previous study (chapter 5) indicate that different attitudes may exist among male partners who do not wish to be involved in biomedical infertility management.

The observation that participants in this study played an active role in initiating the help-seeking process is also not in keeping with reports from the developed world which indicate that women are the prime initiators of treatment (Greil et al., 1988; Wright et al., 1989; Becker and Nachtigall, 1994). This observed difference is more difficult to explain as it can not be attributed to disparities in education or health resources. It is possible that in a poorer, more traditional and patriarchal society such as ours, women have to seek 'permission' from their male partners prior to accessing medical care. Alternatively, our informants may have given 'socially correct' answers. Although the richness of the data and the reports from the fieldworkers indicate that men spoke sincerely about their

involvement and experiences, the tendency of infertile men to present themselves favourably and to have higher 'lie scores' than their female partners has been documented (Berg et al., 1991; Greif, 1997). Further answers pertaining to male attitudes towards infertility treatment in our communities may have to be provided by ethnographic studies which document actual behaviour in men who do and who do not access medical care. Such studies are difficult to conduct and usually require prolonged fieldwork.

Many informants tried to explain why they wanted to have children. It is noteworthy that the reasons forwarded by the informants are largely in keeping with parenthood motives described in a number of European studies which include, among others, well-being, marital completion, happiness, gender-role fulfilment, social control, and continuity (Lalos et al., 1985; Newton et al., 1992; van Balen and Trimbos-Kemper, 1995; Colpin et al., 1998). Motives for parenthood were, however, not systematically explored in this study, and this limits the conclusions that can be drawn from the data. A formal evaluation of parenthood motives was conducted in the study described in chapter 8.

The study involving female informants (chapter 3) demonstrated that several women feared abandonment, divorce, and polygamy because of their inability to conceive. This finding was in keeping with studies from Nigeria, Gambia, Somalia, and Ethiopia which reported that infertility was a major cause for divorce and marital instability and which have been discussed in chapter 1.2 (Omar et al., 1994; Sundby, 1997; Koster-Oyekan, 1999; Tilson and Larsen, 2000; Hollos, 2003; Umezulike and Efetie, 2004). Marital instability, however, did not appear to be a prominent concern among the male participants of this study. These findings suggest that men and women experience the impact of infertility on their relationships differently. There are a number of possible explanations for this apparent difference. Women may experience unnecessary fears despite their partner's reassurances. Women may also have different perspectives either because of the experience of abuse, divorce, and polygamy or because they anticipate that marital instability will carry more negative implications for them than for their male partners. Alternatively, men may not have disclosed their fears or behaviour to the interviewer. The observation that several men acknowledged that involuntary

childlessness could, generally speaking, cause disharmony in the marriage as well as tempt people to test their fertility outside the relationship might suggest that not all informants were entirely honest when interviewed.

Several participants considered infertility as a possible cause for intimate partner violence which is in keeping with the findings presented in chapter 3 and chapter 4. Intimate partner violence has been discussed in greater detail in chapter 4, and the need to analyse further the relationship between infertility and intimate partner violence has been highlighted.

The observation that many men felt socially pressurised and ridiculed and that some reported loss of social status because of their childlessness was a central finding of the study. Negative social consequences secondary to infertility have been documented in several studies from Africa and other developing countries including Bangladesh, Indonesia, Pakistan and India, as discussed in chapter 1.2 (Nabaitu et al., 1994; Gerrits, 1997; Papreen et al., 2000; Riessman, 2000; Tilson and Larsen, 2000; Winkvist and Akhtar, 2000; Hollos, 2003; Setiawan, 2004; Umezulike and Efetie, 2004). There appears to be a widely held belief that these consequences predominantly affect women, but the actual experiences of male partners are poorly documented. Few studies from non-Western industrialised countries have included male respondents, and these suggest that men may be exposed to stigmatisation and loss of social status.

Runganga et al. (2001) conducted in-depth interviews and focus group discussions with men and women in Zimbabwe. Study participants were recruited from biomedical health care services, private practitioners, through social networks and via snowball sampling in both urban and rural settings. All informants had experienced reproductive failure, which not only comprised infertility but also pregnancy loss, stillbirths or having a single child, particularly if this child were female. According to the informants, fatherhood conferred a sense of achievement, continuity, and belonging. In keeping with our own findings, a man without a child was commonly not treated as a man but as a boy. Reproductive failure undermined male gender identity and led to poor self-esteem and a feeling of

worthlessness. Men and women suffering from involuntary childlessness were ridiculed and frequently expected to render social services to the extended family. Claiming paternity from extra-marital relationships was a recognised strategy to avoid the stigma of reproductive failure. Although male reproductive failure was associated with many negative social consequences, the informants indicated that women suffered more.

In a qualitative study from Malawi, Barden-O'Fallen (2005) interviewed 26 men and women with fertility problems in order to assess how these problems were identified and interpreted in a community which placed a high demand on fertility. Recruitment occurred with help of the village chief and by randomly approaching households. Obtaining male participation in the study proved difficult as some men ran away or tried to hide from the interviewer. The few men who were willing to participate indicated that even if the wife was blamed for the inability to conceive, the husband would suffer public humiliation as he was unable to prove himself as a 'real' man. As a consequence he would pressurise his wife to seek treatment and/or attempt to impregnate other women.

Inhorn (2003b, 2004) studied male infertility and stigma in the Middle East through ethnographic research conducted in Egypt in 1988 and 1996 and in Lebanon in 2003. The author reported that in the patriarchal and pronatalist communities of the Middle East men were traditionally expected to have children and achieved social power through the number of their sons. Egyptian informants who acknowledged their infertility described this as an embarrassing, threatening, and profoundly emasculating experience which they often kept secret. Others, however, rejected the diagnosis of male factor infertility as implausible, based on dominant masculinity norms which imply that men cannot be the cause of reproductive failure. As a consequence women carried the main burden of infertility, either because they were allocated the blame for the infertility or because they accepted it as a courtesy stigma in order to protect the social status of their husband (Inhorn 2003b, 2004). In contrast, and to the surprise of the researcher, respondents from the Lebanon expressed the view that male infertility was a medical condition and unrelated to the construct of manhood. The author considered several possible explanations for these discrepant observations. The higher educational levels of Lebanese

men when compared to Egyptian respondents may have modified the negative effects of infertility by offering career-related, alternative life goals. In addition, the advent of assisted reproductive technologies in the Middle East in the last decade may have re-conceptualised male infertility as a medical condition rather than a social failure. Male infertility may have also been a comparatively minor concern for many of the respondents whose lives were shaped by years of civil war and post-war economic crisis. The author, however, also attributed a high refusal rate to the fact that for some Lebanese men male infertility remained a deeply humiliating and emasculating experience (Inhorn, 2004).

In an earlier study Papreen et al. (2000) conducted in-depth interviews with both men and women from urban slum populations in Bangladesh. According to the respondents, infertile men suffered loss of social status as they were prevented from becoming leaders or from stating their opinions in community meetings. Other indications of stigmatisation included exclusion from festive ceremonies (such as weddings) and addressing men as 'infertile' rather than by name. The results of our study are remarkably similar to these findings, although the two studies were conducted in very different environments. Collectively the data indicate that the negative implications of male infertility in the developing world may currently be underestimated and that further research is required (van Zaandvoort et al., 2001).

Contrary to the relative lack of information from the developing world regarding men's experiences of infertility there is a large and growing body of literature on gender similarities and differences from the industrialised world. According to two review articles on infertility and psychological distress, several quantitative studies from North America, Europe and Australia have documented that women suffering from couple infertility score higher levels of psychological distress than their male partners (Wright et al., 1989; Greil, 1997). More recently the need to understand infertility not only as a medical condition but also as a socially constructed reality has been recognised in a number of reports from the USA (Berg et al., 1991; Greil, 1997; Sandelowski, 1999; Inhorn, 2003b). According to this social model of infertility, gender profoundly shapes

the experience of involuntary childlessness (Greil et al., 1988; Becker and Nachtigall, 1991; Berg et al., 1991; Whiteford and Gonzalez, 1995; Sandelowski, 1999). Although gender-role pressures may be gradually changing in the developed world, pregnancy and parenthood appears to remain central to female identity (Berg et al., 1991; Nachtigall et al., 1992; Becker and Nachtigall, 1994; Halman et al., 1994). In contrast, male fertility is seen as a reflection of virility rather than parenthood with the latter being of secondary importance to a man's primary role of a worker and provider (Berg et al., 1991).

The impact that the gender-specific diagnosis of the cause of infertility had on the reactions of men and women to their inability to conceive was further explored in an anthropological study in the USA (Nachtigall et al., 1992). In this study infertile men described their inability to father a child as a profoundly threatening, disabling, stigmatising, and emasculating experience, while the (potentially) fertile partners of infertile women reported fewer negative emotional and social consequences. In contrast, all women reported feelings of loss, role failure, and stigmatisation irrespective of the underlying cause of infertility. These studies highlight the need for health care workers to understand how men and women experience infertility-related distress in order to offer support, promote communication between partners, and find effective interventions.

The results of this qualitative study offered insights into the manner in which men experienced and constructed infertility. To what degree men's experiences are associated with increased levels of psychological distress and how levels of distress among men compare to those previously documented among women is explored in the next chapter.

6.5. SUMMARY

In this study in-depth interviews were conducted with 27 men suffering from couple infertility. The results demonstrated that men had limited knowledge about fertility, infertility, and the principles of modern infertility management. Despite this lack of knowledge the majority of informants were aware of male factor infertility. Most participants were highly motivated to involve themselves in the treatment process. Men appeared largely supportive of their female partners, and many informants had suffered negative social consequences because of their infertility.

CHAPTER 7

PSYCHOLOGICAL DISTRESS AMONG MEN SUFFERING FROM COUPLE INFERTILITY – A QUANTITATIVE ASSESSMENT

7.1 INTRODUCTION

In the previous chapter qualitative research methods were utilised in order to gain insight into the male perspective of involuntary childlessness in our communities. The results demonstrated that for many men this was shaped by negative emotional and social consequences secondary to infertility.

In order to expand our understanding of the impact that involuntary childlessness has on men, a quantitative study was conducted. The primary aim of this study was to assess whether men suffering from couple infertility had higher levels of psychological distress when compared to male partners of pregnant women.

The sample size was the same as the study which measured psychological distress in women (chapter 4), and the Symptom Checklist-90-R (SCL-90-R) was again utilised to assess acute psychological symptom status. This study was, however, conducted five years later. Although this limits the comparability between the two studies, it was considered that a historical comparison of the data may contribute to our understanding of infertility-related psychological distress in men and women.

7.2. METHODS

The study group consisted of 120 men who were recruited at the time of their initial presentation to our infertility clinic. A two-part questionnaire was administered. The first part captured data on socio-demographic characteristics, and in the second part psychological distress was measured with the SCL-90-R as described in chapter 4. Use of the instrument was purchased for this study. In the previous study the withdrawal of six items which were thought to be potentially confounding in our setting did not substantially alter our findings (chapter 4, Table 4.3). The decision was therefore taken not to make changes to the research instrument in this study, and all 90 items of the instrument were administered.

The SCL-90-R is suitable for the assessment of acute psychological symptom status in men and women. The same 90 items are administered, and raw scores are calculated in the same manner. The conversion of raw scores to T scores is, however, gender specific. This means that women are scored against women in the SCL-90-R norm group and men against men (the details of the SCL-90-R norm groups have been presented in chapter 4). The authors of the instrument emphasise the importance of gender-specific norms, as women in the 'American culture' report more psychological symptoms and higher levels of distress secondary to emotional conflicts when compared to men.

A local control group was again added in order to improve validity. This group consisted of 120 men who accompanied their female partners, who had documented low risk pregnancies, for a routine antenatal visit at a level one public health care facility or for a routine 20 week ultrasound scan at Groote Schuur Hospital. Men in the control group had the same questionnaire administered except for a question on the duration of infertility (study group only).

Three research assistants were involved in the data collection. Informants who reported high levels of distress were counselled immediately after the interview and referred for appropriate psychological support.

The study measuring psychological distress among women (Chapter 4) also included a quantitative measure of themes identified through the qualitative research described in chapter 3. The results demonstrated congruency between the qualitative and quantitative data. These themes (reproductive health knowledge or treatment-seeking behaviour) were therefore not explored again in this study. Furthermore, we did not consider the setting of this study suitable for the collection of reliable information regarding intimate partner abuse, and no such data were collected.

7.2.1. Statistical Analysis

For the comparison of the socio-demographic characteristics between the two groups t-test statistics (for numerical variables) and the chi-square test (for categorical variables) were applied. The Fisher's exact test was utilised if the number of observations in a given category was very small (less than five) as the chi-square test is not sufficiently robust under these conditions.

The Wilcoxon rank sum test was employed to assess differences of T scores between infertile and fertile men as the data were skewed (unlike the female data described in chapter 4) and the t-test cannot be used under these circumstances.

In addition, a historical comparison was conducted between infertile men and infertile women and between male and female controls. The comparison of the different socio-demographic variables between these groups was made with the help of the t-test, the Fisher exact test, and the Wilcoxon rank sum test. For comparison of the T scores the Wilcoxon rank sum test was again utilised in order to accommodate the skewed distribution of the male data.

Linear regression analysis was conducted if differences in the socio-demographic variables between cohorts were observed in order to assess the impact of these variables on the T scores.

7.3. RESULTS

7.3.1. Socio-Demographic Characteristics

In Table 7.1 the socio-demographic characteristics of the study group and the control group are summarised. Infertile men were older, more likely to be married, and had lower levels of education when compared to men in the control group ($p<0.05$). The different languages and religious denominations were equally represented in both groups.

Although fewer men in the study group had at least one live child when compared to the control group, the difference did not reach statistical significance. Of the 49 infertile informants who had a child the majority ($n=36$) was childless in their current relationship.

Table 7.1. Socio-demographic characteristics of study group and control group

	Study Group N = 120		Control Group N = 120		P value
Age (years)					
Mean	33.3		29.5		< 0.05
Range	22 – 58		20 – 49		
Live children	N	%	N *	%	ns
Yes	49	40.8	76	63.3	
No	71	59.2	41	34.2	
Marital Status	N	%	N	%	< 0.05
Married by law	95	79.2	82	68.9	
Married by religious/ cultural practices	8	6.7	2	1.7	
Common law marriage	17	14.2	35	29.2	
Home language	N	%	N	%	ns
Xhosa	33	27.5	26	21.8	
Afrikaans	36	30	14	11.8	
English	37	30.8	77	64.7	
Other	14	11.7	2	1.7	
Education	N	%	N	%	< 0.05
1 – 7 years of education	23	19.2	3	2.5	
8 – 12 years of education	70	58.3	74	61.7	
Tertiary education	27	22.5	43	35.8	
Religious affiliation	N	%	N **	%	ns
Christian	78	65	63	52.9	
Muslim	25	20.8	37	31.1	
No affiliation	15	12.5	14	11.8	
Other	2	1.7	5	4.2	
ns = not significant * = missing data: n = 3 ** = missing data: n = 1					

7.3.2. Psychological Symptom Status

The results of the SCL-90-R are presented as mean T scores and their standard deviations (Table 7.2). The mean T scores of the control group centred closely around 50 which is the mean of the SCL-90-R norm group. The mean T scores of the study group were consistently elevated. The differences between the mean T scores of the study group and the control group were statistically significant on all scales. These differences persisted when controlling for age and educational levels.

Table 7.2. Mean T scores among study group and control group

SCL-90-R Scales	Study group N = 120	Control group N = 120	P value
Somatisation	53.6 ± 11.6	47.3 ± 8.6	< 0.0001
Obsessive Compulsive	57.9 ± 11.4	51.6 ± 10.6	< 0.0001
Interpersonal Sensitivity	59.7 ± 10.8	51.2 ± 10.3	< 0.0001
Depression	58.7 ± 10.3	50.1 ± 9.5	< 0.0001
Anxiety	56.2 ± 11.9	47.1 ± 9.8	< 0.0001
Anger – Hostility	55.7 ± 10.9	50.6 ± 9.7	< 0.0001
Phobic Anxiety	58.2 ± 11.1	50.6 ± 8.6	< 0.0001
Paranoid Ideation	59.8 ± 10.0	52.0 ± 11.0	< 0.0001
Psychoticism	58.9 ± 10.5	50.0 ± 8.5	< 0.0001
Global Severity Index	59.7 ± 10.7	50.1 ± 10.5	< 0.0001
PSDI *	56.9 ± 10.7	50.8 ± 12.0	< 0.0001
Positive Symptom Total	58.2 ± 9.0	50.3 ± 10.2	< 0.0001

Values are mean T scores ± SD Norm group: mean = 50

* PSDI = Positive Symptom Distress Index

The range of the standard deviations was similar between the two groups of informants indicating similar variability in the data. The standard deviations furthermore reflect that men in both groups scored along a continuum of psychological functioning ranging from low to high levels of psychological distress.

Infertile men scored highest on the paranoid ideation scale. The next highest mean T score was recorded on the interpersonal sensitivity scale, followed by the psychoticism scale and then the depression scale. The lowest scores were recorded on the somatisation scale. The interpretation of these scales has been described in chapter 4. In contrast, as already mentioned, there were no noteworthy elevations of the mean T scores on any of the sub-scales in the control group.

Men suffering from infertility, therefore, had significantly higher T scores on all scales of the instrument when compared to both the SCL-90-R norm group and the control group. The scores of men in the control group were very similar to the SCL-90-R norm group. The observed T score elevations among infertile men were, however, within one standard deviation of the mean of the SCL-90-R norm group. They are, therefore, not indicative of disordered psychological functioning but reflect psychological distress levels in the upper range of normal.

7.3.3. Historical Comparison of the Male and Female Data

Men in both groups (subjects and controls) were significantly older when compared to their female counterparts ($p < 0.05$). As demonstrated in Table 7.3 more infertile men than infertile women had at least one live child ($p < 0.05$). There was no gender difference in the level of education, but both female cohorts differed from the male cohorts with regard to religious affiliations and the distribution of home languages (Table 7.3).

Table 7.3. Socio-demographic characteristics of male and female study group and male and female control group

	Study Group			Control Group		
	Men N = 120	Women N = 120	p value	Men N = 120	Women N = 120	p value
Live children						
Yes	49	37	< 0.05	76 *	83	ns
No	71	83		41 *	37	
Home language						
Xhosa	33	39	< 0.05	26	42	< 0.05
Afrikaans	36	27		14	22	
English	37	54		77	56	
Other	14	-		2	-	
Religious affiliation						
Christian	78	98	< 0.05	63	108	< 0.05
Muslim	25	17		37	10	
No affiliation	15	5		14	2	
Other	2	-		5	-	

ns = not significant
* = missing data: n = 3

The mean T scores of infertile men and infertile women are depicted in Table 7.4. Table 7.5 summarises the results of the two control groups. Among both subjects (infertile individuals) and controls women scored significantly higher on all scales when compared to men, with the exception of the Positive Symptom Distress Index (PSDI), for which a significant gender difference existed only among controls. The PSDI is a marker of symptom intensity. The differences in T scores between male and female informants persisted after controlling for socio-demographic variables (age, home language, and religion).

Table 7.4. Mean T scores among infertile men and infertile women (male and female study group)

SCL-90-R Scales	Men N = 120	Women N = 120	P value
Somatisation	53.6 ± 11.6	61.0 ± 7.6	< 0.0001
Obsessive Compulsive	57.9 ± 11.4	62.7 ± 7.4	< 0.0001
Interpersonal Sensitivity	59.7 ± 10.8	65.2 ± 6.9	< 0.0001
Depression	58.7 ± 10.3	63.6 ± 5.6	< 0.0001
Anxiety	56.2 ± 11.9	62.1 ± 7.9	< 0.0001
Anger – Hostility	55.7 ± 10.9	66.2 ± 8.2	< 0.0001
Phobic Anxiety	58.2 ± 11.1	63.3 ± 7.4	< 0.001
Paranoid Ideation	59.8 ± 10.0	65.9 ± 6.2	< 0.0001
Psychoticism	58.9 ± 10.5	68.0 ± 7.1	< 0.0001
Global Severity Index	59.7 ± 10.7	65.9 ± 6.0	< 0.0001
PSDI *	56.9 ± 10.7	59.5 ± 8.3	ns
Positive Symptom Total	58.2 ± 9.0	66.0 ± 6.3	< 0.0001

Values are mean T scores ± SD

Norm group: mean = 50

* PSDI = Positive Symptom Distress Index

Table 7.5. Mean T scores among fertile men and women currently using contraception (male and female control group)

SCL-90-R Scales	Men N = 120	Women N = 120	P value
Somatisation	47.3 ± 8.6	54.0 ± 10.8	< 0.0001
Obsessive Compulsive	51.6 ± 10.6	58.9 ± 8.9	< 0.0001
Interpersonal Sensitivity	51.2 ± 10.3	59.4 ± 9.0	< 0.0001
Depression	50.1 ± 9.5	57.6 ± 9.8	< 0.0001
Anxiety	47.1 ± 9.8	54.3 ± 11.3	< 0.0001
Anger – Hostility	50.6 ± 9.7	56.5 ± 10.0	< 0.0001
Phobic Anxiety	50.6 ± 8.6	59.8 ± 10.0	< 0.001
Paranoid Ideation	52.0 ± 11.0	59.5 ± 9.4	< 0.0001
Psychoticism	50.0 ± 8.5	61.2 ± 10.0	< 0.0001
Global Severity Index	50.1 ± 10.5	59.3 ± 9.5	< 0.0001
PSDI *	50.8 ± 12.0	56.7 ± 11.0	< 0.001
Positive Symptom Total	50.3 ± 10.2	58.5 ± 8.6	< 0.0001

Values are mean T scores ± SD Norm group: mean = 50

* PSDI = Positive Symptom Distress Index

7.4. DISCUSSION

This is the first study from South Africa which measured psychological distress in men suffering from couple infertility. Our results demonstrated significant differences in the acute psychological symptom status of infertile men when compared to fertile controls. The mean T score elevations of infertile men, however, did not reach levels indicative of disordered psychological functioning but reflected distress levels in the upper range of normal.

The study group and the control group differed in age, marital status, and educational status. There are several possible explanations for the observed differences. Infertile men

may be older when compared to fertile men because of the time spent waiting for conception and because of possible delays in accessing infertility treatment. The negative association between infertility and educational status may be due to risk-taking in sexual behaviour (secondary to inadequate reproductive health knowledge and education) as well as delayed help-seeking and difficulties in accessing quality health care for sexually transmitted diseases. Alternatively, men with higher educational levels may be more likely to present to antenatal care facilities, either because they recognise the importance of male partner involvement in antenatal care or because they are better able to negotiate time away from work when compared to men with lower educational status.

The difference in marital status between infertile and fertile men may be related to the fact that childbearing is particularly important for married couples in our communities and, as a result, married men may be more likely to present to the infertility clinic when compared to men living in common law relationships. Importantly, however, these observed differences in socio-demographic characteristics between infertile and fertile men did not influence the findings of the SCL-90-R as the differences in T scores persisted when controlling for socio-demographic characteristics.

The results of this study must be related to the qualitative findings described in chapter 6. Male respondents in the qualitative study expressed a deep desire for a child, described intense emotional reactions such as emptiness, sadness and anger, and many experienced considerable social pressure as well as, on occasion, ridicule, and stigmatisation. The current study indicates that men suffering from couple infertility experienced psychological distress levels in the upper normal range. The findings of the current study therefore depict a male reality of infertility that is, perhaps, less negative and distressing than what has been reported from the qualitative study.

A number of factors need to be considered when interpreting this observed discrepancy. Firstly, the higher mean T scores in the study group imply that when the standard deviations are taken into account, more subjects than controls have T scores indicative of a clinically significant psychological distress reaction (i.e. T scores > 60). Furthermore, a

degree of discrepancy between quantitative and qualitative data is not a novel finding. Researchers from the USA have previously reported that the quantitative literature does not appear to reflect the intensity of infertility-related psychosocial distress described in qualitative studies (Berg, 1994; Greil, 1997). The fact that the standardised instruments used in quantitative research may lack sensitivity in the context of infertility may be a possible explanation for this discrepancy (Berg, 1994).

It must also be emphasised that qualitative and quantitative studies are not competing but complementary research methods. The aim therefore is not to assess which of our two studies involving male respondents is likely to reflect the reality of infertility more 'accurately', but to take cognisance how the individual findings help us understand the male perspective of infertility in our communities. Our research indicates that in our communities most men are exposed to negative emotional and social consequences associated with involuntary infertility, but they do not, on average, suffer from abnormally high levels of psychological distress or show signs of psychopathology. For some men infertility is, however, associated with psychological distress above the normal range. It may be hypothesized that these individuals are particularly vulnerable to the negative emotional and social consequences of infertility and/or have fewer coping skills to address these.

The historical comparison between the current study and the study described in chapter 4 reveals several observations. Significantly fewer infertile women had at least one live child when compared to infertile men. This may imply that more women than men suffer from primary infertility in our community. Alternatively, infertile women may have encountered previous pregnancy complications (e.g. ectopic pregnancy or septic miscarriage), which resulted in pregnancy failure as well as infertility. As discussed in chapter 1.2, pregnancy complications contribute to the high rate of female infertility in Africa.

The differences in home language and religious affiliations between the male and female respondents were unexpected findings for which we do not have a suitable explanation. It

must, however, be emphasised that the difference in T scores between men and women was not influenced by the disparate socio-demographic variables.

The historical comparison demonstrated that infertile women had significantly higher T scores on all but one scale when compared to men suffering from couple infertility. These findings are in keeping with the perception that in South Africa women carry the main social and emotional burden associated with infertility, without ignoring the fact that men also experience stress and distress secondary to involuntary childlessness.

A similar gender difference pertaining to acute psychological symptom status was, however, also found in the control groups. There are two possible interpretations of this finding. Women in our community may experience higher levels of psychological distress *per se* when compared to women in the industrialised world (SCL-90-R norm group) and to men in our communities. If the experience of infertility is added to this 'background level' of elevated psychological distress, women move into the above normal range of acute psychological symptom status while men continue to function in the upper range of normal. Alternatively, general stress levels in our communities may have decreased in the last five years. This explanation is less likely as no significant social, economic or political changes have occurred in this time period. The time difference between the two studies, as previously stated, limits the comparability of the data, and further studies are required in order to assess how gender influences infertility-related psychological distress in our communities.

Our findings need to inform the management process of infertile couples. They highlight once again the importance of integrating male partners into infertility management and of recognising their specific needs in the context of patient-centred care. The latter requires an understanding of the patients' perspective and this study makes an original contribution in this regard. The issues pertaining to patient-centred care have been discussed in greater detail in chapter 4.

There is a paucity of data from African countries with which to compare our findings. The little that is known about the male experience of infertility in Africa has been derived from qualitative studies, and these have been discussed in the previous chapter (chapter 6). In contrast, several studies from the industrialised world have assessed psychological distress among infertile men and women, and in some of these the SCL-90-R was utilised. These latter studies have been presented in chapter 4, but further discussion of relevant findings relating to men and to the difference between men and women is presented here.

In a study from Germany, Wischmann et al. (2001) demonstrated that women suffering from couple infertility had T score elevations on six primary symptom dimensions and on all three global indices of distress (chapter 4). In the same study male participants had elevated T scores on only two scales (paranoid ideation, mean T score: 50.9 ± 11.8 ; somatisation, mean T score: 51.4 ± 11.5). The absolute differences between subjects and the SCL-90-R norm group were small. The authors concluded that infertile couples differed in only few psychological variables from the norm group, that women had a 'somewhat higher degree of stress' when compared to men, and that a sub-group of couples were sufficiently stressed to warrant professional psychological intervention.

In a study involving 104 infertile couples, Berg and Wilson (1990) reported that women showed moderate distress reactions (T scores between 60 and 65) on three scales of the SCL-90-R (interpersonal sensitivity, depression and psychoticism) and men on one scale (interpersonal sensitivity). The authors emphasised the importance of not interpreting elevated T scores as 'abnormal' unless they exceeded a score of 60 (equal to the 84th percentile of the norm group and equal to one standard deviation above the mean). The only gender difference was observed on the somatisation scale on which women scored higher than men, but the mean T score was less than 60. The authors concluded that the overall psychological profile of both men and women was indicative of psychological strain (characterised by negative mood, tension, worry and interpersonal alienation) and that men and women were similarly affected by infertility.

In a longitudinal study Daniluk (1988) assessed the emotional impact of the diagnostic work-up for infertility. The study cohort consisted of 63 primarily infertile couples who attended a Canadian Endocrine infertility clinic. Six questionnaires, including the SCL-90-R were administered in four settings (immediately after the first consultation, four weeks later during the diagnostic work-up, shortly after the cause of infertility was established, and again six weeks later). The mean T scores were below 60 in all four sessions with highest scores recorded in the first session. A gender difference was only observed at session 3 (following the diagnosis of the cause of infertility) at which women scored higher on four scales when compared to men. The authors noted that the average participant experienced 'some degree' of psychological distress which was neither extreme nor debilitating, but required the availability of psychological services as part of infertility management.

In summary, these three studies, which were conducted in the industrialised world and therefore in a different social environment when compared to our study, reported that infertility was associated with some degree of psychological distress, but not with disordered psychological functioning. In addition it was noted, that there was overall little gender difference in the psychological functioning of infertile couples.

The comparison between these and our studies reveals both similarities and differences. Although the absolute T score elevations among male subjects in our study were higher when compared to men in the other studies, they were within a similar range (i.e. within one standard deviation of the mean). The gender difference observed in our study appears, however, to be greater both in width (number of scales recording gender differences) and depth (degree of difference in T scores) when compared to the other studies. This observation suggests that gender shapes the experience of infertility more profoundly in South Africa when compared to Western industrialised countries, because of a greater burden imposed on women. The comparison between the different studies must, however, be made with due cognisance of the fact that differences exist in the research methods and cultural settings across the various studies, that we did not

investigate couples, and that the SCL-90-R is not formally validated in South Africa. These limitations have been addressed in chapter 3.

It has been argued that the elevated levels of psychological distress in infertile men and, particularly, among infertile women reflect the reality of infertility in our communities which is often shaped by negative emotional and social consequences. As such the distress is presumed to be the consequence of infertility. This interpretation appears to be supported by the qualitative studies described in chapters 3 and 6. The possibility that elevated psychological distress may be the cause rather than the consequence of infertility must, however, also be considered. The research methodology applied in our two studies does not allow us to draw conclusions regarding the temporal relationship between infertility and psychological distress, nor do any other studies from African countries contribute in this regard. There is, however, an extensive literature from the industrialised world on the cause and effect relationship between infertility and psychological distress. While a detailed review of this literature is beyond the scope of this chapter some relevant and recent publications will be discussed.

In a prospective study conducted in France, Stoleru et al. (1996) explored the aetiological role of psychological factors in infertility. The study cohort comprised 63 nulliparous couples who had recently discontinued contraception (and whose fertility status was undetermined at the time of recruitment) and 30 couples with known infertility. After twelve months of follow-up 42 of the 63 couples with previously undetermined fertility status had conceived. All participants completed a number of psychological assessments at baseline and twelve months later. Among men the inadequate integration of the wish for a child into the marital/sexual relationship and an elevated Sexual Problem Score (which captured 'qualitative and quantitative aspects of sexual life' with no further details given) were found to be a possible cause of infertility. In women, psychological factors were not found to play an aetiological role in infertility.

Hjollund et al. (1999; 2004) conducted a longitudinal study in Denmark in order to ascertain the effect of psychological distress on male and female reproductive function.

The authors recruited 430 couples who were trying to conceive for the first time. Couples were followed up for six months or until pregnancy was diagnosed. Female participants kept a menstrual diary and psychological distress was measured in the mid-luteal phase in both partners via the General Health Questionnaire, a 30-item inventory. Semen quality was assessed monthly from the time of enrolment. According to the results, high levels of distress among women were associated with reduced cycle fecundity (OR 0.6; 95% CI 0.4-1.0) but only in women who had a prolonged menstrual cycle (cycle length > 34 days). The postulated mechanism involved neuro-endocrinological changes resulting in a disturbance of the normal menstrual cycle (Hjollund et al., 1999). In contrast, psychological distress in men had little or no impact on semen quality and fecundability, except for a subgroup of male participants who had a sperm density below 20 million/ml and who had slightly reduced odds of pregnancy (adjusted OR 0.06; CI 1.01-0.58). The authors considered the possibility that men with low sperm-concentrations represented a stress-vulnerable group but concluded that male stress had overall little impact on male reproductive function (Hjollund et al., 2004).

The association between male infertility and occupational psychological stress was explored in a prospective study in Israel (Sheiner et al., 2002). Male partners of couples attending a fertility clinic at the Soroka University Medical Centre, Beer-Sheva, were recruited consecutively. The study group consisted of 106 men with male factor infertility, and the control group comprised 66 men whose female partners were diagnosed to be infertile. A semen analysis was performed on all participants according to the WHO criteria and the Tygerberg strict criteria for sperm morphology. Occupational stress was assessed by measuring burn out (comprising three scales on physical and emotional fatigue, tension, and listlessness), cognitive weariness, job strain and job satisfaction. Men in the study group had significantly higher scores on all measures of occupational burn out and stress when compared to men in the control group. The authors recommended that occupational psychological stress should be assessed in all men suffering from couple infertility.

Collectively these studies provide evidence that psychological distress may precede infertility in some individuals. Reviews on the cause and effect relationship between infertility and psychological distress have either concluded that the existing data are inconclusive or that infertility is generally more likely to cause psychological distress than *vice versa* (Wright et al., 1989; Golombok, 1992; Greil, 1997). Although there is a lack of data from African countries which provide insight into the cause and effect relationship between infertility and psychological distress, it appears highly plausible that the many negative emotional and social consequences associated with infertility are the cause of considerable psychological distress, especially among women.

A recent study from the USA, conducted by Mindes et al. (2003), offered insight into the mechanism by which infertility-related negative social interactions may affect the psychological well-being of women. This study has already been presented in chapter 1.2.8. Pertinent to this discussion is the observation that unsupportive social responses were found to cause psychological distress through a process involving threat appraisal (i.e. the construction of infertility as a threat to relationships, health, career, life goals and financial security) and negative coping strategies, such as avoidance coping. Avoidance coping encompasses cognitive and emotional activity that is oriented away from a threat. In contrast, approach coping involves strategies that are directed towards a stressful life event (Roth and Cohen *as cited in*: Skinner et al., 2003). Mindes et al. (2003) noted that avoidance coping, although possibly reducing distress in the short-term, diverted attention from the negative life event thereby preventing the successful processing of the event. This results in maladjustment when compared to approach coping strategies, such as seeking information or emotional support or engaging in cognitive restructuring (Mindes et al., 2003). The observation that denial and avoidance coping is associated with poor adjustment to infertility and with elevated levels of fertility-related stress has also been reported by others (Sabatelli et al., 1988; Schmidt et al., 2005). To what extent threat appraisal and negative coping strategies mediate the relationship between negative social consequences secondary to infertility and psychological distress in the African context requires further research.

The studies described in this chapter and in the chapters 3, 4 and 6 have documented the importance that infertile couples attach to having children and outline some of the consequences of the inability to conceive. They indicate that parenthood plays a central role in our communities. This research does, however, not allow us to conclude why children and parenthood are so highly valued in our communities. This question is addressed in the next chapter.

7.5. SUMMARY

Acute psychological symptom status was measured in 120 men suffering from couple infertility and in 120 fertile men using the SCL-90-R. While the mean T scores of infertile men were significantly higher on all scales when compared to fertile men they were within the range of normal psychological functioning. Our results indicate that for men infertility is associated with increased levels of distress but that on average this distress does not exceed the upper range of normal psychological functioning. A comparison with data collected from women in a previous study (chapter 4) showed a significant gender difference between male and female subjects as well as between male and female controls.

CHAPTER 8

MOTIVATIONS FOR PARENTHOOD – A PILOT STUDY

8.1. INTRODUCTION

As outlined in chapter 1.2.4., parenthood is a central life goal in most societies (Becker and Nachtigall, 1994; Edelman et al., 1994; Daniluk, 1997; Fidler and Bernstein, 1999). Despite this apparently simple and universal observation, answers to the question what motivates men and women to have children are complex, varied, and, at times, elusive (Hoffman and Hoffman, 1973). The need to document motives for parenthood and to study their interaction with other variables has been highlighted, and different approaches to this task have been discussed in chapter 1.2.4. (Hoffman and Hoffman, 1973; Edelmann et al., 1994). Some of these approaches appear particularly complex and are based on an in depth knowledge of sociology, anthropology, and psychology (Veevers, 1973; Miller, 1992; Miller, 1994).

From the perspective of the health sciences, parenthood motives can be explored by asking infertile men and women why they want to have children. Infertile couples probably do not differ from fertile couples in their reasons for wanting a child. Their inability to conceive, however, usually induces reflection as to why a child is desired. This results in the manifestation of parenthood motives which often remain latent and thus difficult to study in the general population (van Balen and Trimbos-Kemper, 1995). Infertile couples, therefore, represent a suitable cohort for the study of parenthood motives. In addition, an understanding of why people wish to have a child offers important insights into the difficulties and losses with which infertile couples may have to deal (van Balen, 2001). This understanding plays an important role in the delivery of patient-centred care.

Van Balen and Trimbos-Kemper (1995) studied parenthood motives among infertile couples in the Netherlands. Based on the findings of this and two other Dutch studies by Mozes (1989) and van Luijn and Parent (1990) (*as cited in*: van Balen, 2001), van Balen concluded in a subsequent report on infertility in Western countries that parenthood was mostly desired for the expected feelings of love and happiness (van Balen, 2001). In contrast, motives relating to social reasons and norms featured less prominently. He also suggested that infertility in Western societies carried few social consequences and that couples decided about parenthood without interference from others (van Balen, 2001).

Studies from African countries present contrasting findings. As discussed in chapter 1.2, reports from Cameroon, Nigeria, Mozambique, Gambia and Chad indicate that society and social norms strongly influence why men and women want to have children (Feldman-Savelsberg, 1994; Hollos, 2003; Gerrits, 1997; Sundby, 1997; Leonard, 2002). Any conclusions drawn from these studies are limited by the fact that these observations are derived from qualitative work on fertility and infertility in general and not from a structured analysis of parenthood motives.

The primary aim of this study was to assess parenthood motives among infertile couples with the use of a standardised instrument, the parenthood-motivation list (van Balen and Trimbos-Kemper, 1995). The secondary aim was to explore attitudes towards fertility and infertility treatment of HIV-infected individuals in the same study cohort, and to assess whether an association existed between these attitudes and parenthood motives. This part of the study is presented in the next chapter.

It was anticipated that the results of this study would expand our understanding of parenthood motives. Insight would also be gained about how reproductive decisions and attitudes may be influenced by the HIV/AIDS epidemic in our communities.

8.2. METHODS

Fifty couples who attended the infertility clinic and in whom both partners tested negative for HIV were asked to participate in this study. No pre-existing data were available from which to perform a power analysis. It was anticipated that 50 couples would allow the piloting of the parenthood-motivation list in our community and that the findings generated by this study would offer information which may be used for further research. Patients were recruited at the infertility clinic immediately prior to their second medical consultation. As outlined in chapter 2.2.1, all couples had undergone routine infertility investigations and HIV testing following their first clinic appointment. At the time of recruitment, patients were unaware of the results of these investigations. Participants were informed about their HIV test result prior to the start of the interview. Post-test counselling was conducted at the end of the interview.

Couples were recruited consecutively until the desired sample size was reached. Recruitment was dependent on both partners testing HIV negative, being present at the scheduled visit, and being willing to participate in the study. All interviews were conducted by one multilingual professional nurse in the preferred language of the informant.

A three-part questionnaire was administered. The first part captured basic socio-demographic information. The second part contained a questionnaire on parenthood motives based on the work of van Balen and co-workers (van Balen and Trimbos-Kemper, 1995). Following personal communication with Dr van Balen, this instrument had been forwarded to our unit for use in our studies. The questionnaire captures quantitative data on four items relating to parenthood as described below. The complete version of this questionnaire is presented in Appendix D.

1. Motives for parenthood.

These are evaluated through the parenthood-motivation list. This list comprises 18 items which reflect six parenthood motives (Table 8.1). The six parenthood motives are constructed as follows: Happiness refers to the expected feelings of affection and happiness in the relationship with children. Well-being comprises positive effects on the family relationship. Parenthood reflects being a mother or father as a source for life-fulfilment. Identity implies that children facilitate transition to adulthood and strengthen identity. Continuity comprises the wish to live on through children after death and to have support in old age. Lastly, social control refers to the implicit or explicit external pressure on the couple to procreate (van Balen and Trimbos-Kemper, 1995).

The response to each of the 18 items is measured on a three-point scale (strong agreement, partial agreement, and disagreement). Strong agreement with any one (or more) of the three items pertaining to a particular motive is interpreted as this motive to be present.

2. Reflection.

Reflection is assessed by asking informants whether they think about why they wanted a child. Informants are offered the choice of one of three possible answers ('never', 'sometimes' and 'often').

3. Strength of desire for a child.

This is measured with the help of Likert scales and the two questions 'How strong is your wish to have a child / another child?' (Six-point scale; 1 = I do not really care that much; 6 = I am willing to give absolutely everything for it) and 'How do you currently feel about the fact that you may never have a child / another child of your own?' (Seven-point scale; 1 = It does not affect me; 7 = It is the worst thing that ever happened to me).

Table 8.1. Parenthood-motivation list

Item	Motive	Number *
It is nice to have children around	Happiness	1
To have unique relationship with the child	Happiness	10
Bringing up children brings happiness	Happiness	12
It makes the relationship with your partner complete	Well-being	3
Children make life complete	Well-being	8
It gives you a goal to live for	Well-being	13
It is obvious to have children	Identity	4
It is a sign of being grown-up	Identity	14
It is the nature of man / woman	Identity	16
It fulfils motherly / fatherly feelings	Parenthood	2
Parenthood is satisfying	Parenthood	6
To experience pregnancy and birth	Parenthood	11
Your environment (others, family) expect it of you	Social control	9
Others around me have children	Social control	17
To avoid being an outsider	Social control	18
To continue the family name / tradition	Continuity	5
Not to be alone when you are old	Continuity	7
To have something of yourself continue living after you are dead	Continuity	15

* Order in which item is asked in the list.

4. Consensus.

Consensus between partners regarding their desire for a child is assessed by asking the informant how the strength of their wish for a child compared to that of their partner's ('stronger', 'as strong', 'not as strong').

The third part of the questionnaire was designed for the purpose of this study. It assessed informants' knowledge of the impact of HIV/AIDS on human reproduction

and attitudes towards the delivery of infertility management to HIV-positive clients through both closed and open-ended questions. Details of this part of the questionnaire are presented in chapter 9.

8.2.1. Statistical Analysis

The analysis of the data was aimed at answering the following three questions. (1) Is the parenthood-motivation list a valid instrument in our setting? (2) Did men and women differ in their socio-demographic characteristics and in their responses to the parenthood-motivation list? (3) Does an association exist between parenthood motives and strength of desire for a child?

In the original publication the validity of the six categories of parenthood motives was assessed through factor analysis with principal component analysis and varimax rotation (van Balen and Trimbos-Kemper, 1995). This analysis demonstrated that for infertile men and women living in the Netherlands the four categories of happiness, continuity, social control and well-being were different factors or motives. Although according to the factor analysis the categories parenthood and identity appeared to be a single motive, the authors elected to maintain the six categories of parenthood motives in their instrument 'as these had been discerned in previous studies and on theoretical grounds' (van Balen and Trimbos-Kemper, 1995).

For the statistical analysis of this study it was considered necessary to test the model before applying it in the analysis of the data. The main objective of this test was to assess whether in our study population the 18 items coded for the six parenthood motives (i.e. three items per motive – also referred to as a 'triplet' in the further analysis). Two possible approaches were considered, namely factor analysis (as in the original publication) and latent trait analysis. Factor analysis involves assessing whether the correlation structure of each triplet can be explained by a single factor (i.e. parenthood motive). The correlation structure of any three variables can, however, be quite easily

explained by a single factor and as such does not represent a sufficiently stringent test of the model.

Latent trait modelling is a stricter test and was therefore utilised. According to latent trait modelling the observed pattern of responses to each triplet is compared in detail with the pattern predicted by the model. The results of the latent trait analysis indicated a satisfactory fit of our data and the instrument was therefore assessed as being valid for our study. The details of the latent trait analysis are presented in Appendix F.

After testing the actual model through the latent trait analysis, a factor analysis was conducted as described in the original publication. This analysis was undertaken to add additional support to the validity of the instrument in our setting and in order to use the calculated factor scores in the further analysis of the data. In keeping with the results of the latent trait modelling, the results of the factor analysis demonstrated that the correlation structure of the 18 items was adequately explained by the 6 motive categories (see Appendix F for details).

The paired t-test and the McNemar test were utilised in order to assess whether gender difference existed in the socio-demographic characteristics of the participants and in the responses to the parenthood-motivation. Consideration was given to the fact that the data may not be normally distributed, but the t-test is known to be robust under these conditions secondary to the permutation distribution of the t-statistics.

The association between the six parenthood motives and the strength of desire for a child (as measured through the two Likert scales) was assessed by first calculating the six factor scores and by then assessing the correlation co-efficient between each factor score and the Likert scale score. Correlation coefficients greater than 0.286 were indicative of a statistically significant association ($p < 0.05$).

8.3. RESULTS

8.3.1. Socio-Demographic Characteristics

The basic socio-demographic information of the participants is captured in Table 8.2. Female respondents were on average 3.4 years younger than their male partners ($p < 0.005$). More women than men had no live child ($p < 0.05$). Sixteen women and 22 men had at least one live child, but of these only six couples had a live child in union. No gender difference was observed in the level of education or the occupational status.

Couples reported a mean duration of infertility of 4.6 years (range: 1-12 years). Thirty seven couples were married by South African law, ten couples lived in a common law marriage, and three couples were married according to religious/cultural practices. The capture of ethnic group rather than home language of the informant was not intended, but due to an error in the socio-demographic questionnaire. The analysis of this information demonstrated that no white informants participated in this study, because they did not fulfil the study criteria during the recruitment period.

Table 8.2. Socio-demographic characteristics

	Women N = 50	Men N = 50	P value
Age (years)			
Mean	29.5	32.9	< 0.005
Range	20 - 38	21 – 54	
Live children	N	N	< 0.05
Yes	16	22	
No	34	28	
Population group	N	N	ns
Black	20	20	
Mixed ancestry	30	30	
Education	N	N	ns
1 – 7 years	6	5	
8 – 12 years	40	39	
Tertiary education	4	6	
Occupation	N	N	ns
Professional	4	3	
Skilled	13	25	
Semi-skilled / manual	18	16	
Not employed	15	6	
ns = not significant			

8.3.2. Parenthood Motives

Table 8.3 demonstrates the presence of parenthood motives among informants. As described earlier a parenthood motive was considered to be present in an individual if he/she answered ‘I strongly agree’ to any one or more of the three items belonging to the motive. All six motives were frequently endorsed by the participants. Although women endorsed all motives more often than men, none of the differences was statistically significant. Happiness, the most frequently mentioned motive, was endorsed by all but

one informant. Social control was the parenthood motive with the lowest prevalence, but it was still endorsed by over two thirds of women and by over half of male respondents.

Inherent in the observation that all motives were frequently endorsed is the fact that participants agreed with several motives simultaneously. None of the informants had only one motive for parenthood. Ninety three participants had at least four motives for wanting a child. Female informants endorsed more motives simultaneously (mean 5.22) when compared to male informants (mean 4.80; $p=0.028$).

Table 8.3. The presence of parenthood motives among study participants

Parenthood Motive	Women N = 50	Men N = 50	P value
Happiness	50	49	ns *
Parenthood	48	48	ns
Identity	45	40	ns
Well-being	43	41	ns
Continuity	40	34	ns
Social control	35	28	ns
ns = not significant			

Informants' responses to the individual items of the parenthood-motivation list are summarised in Table 8.4. Male and female responses are presented jointly (a breakdown of female and male responses is presented in Table F.1 of Appendix F). A gender difference was observed in four of the 18 items all of which were endorsed more frequently by women when compared to men. This difference did, however, not translate into a gender difference at the level of parenthood motives. Importantly, as in Table 8.3, Table 8.4 demonstrates that even items on the lowest ranks (in terms of frequency of endorsement) were still strongly enforced by several of the informants.

Table 8.4. Responses to the individual items of the parenthood-motivation list

Responses 1 = I do not agree

Responses 2 = I agree to some extent

Responses 3 = I strongly agree

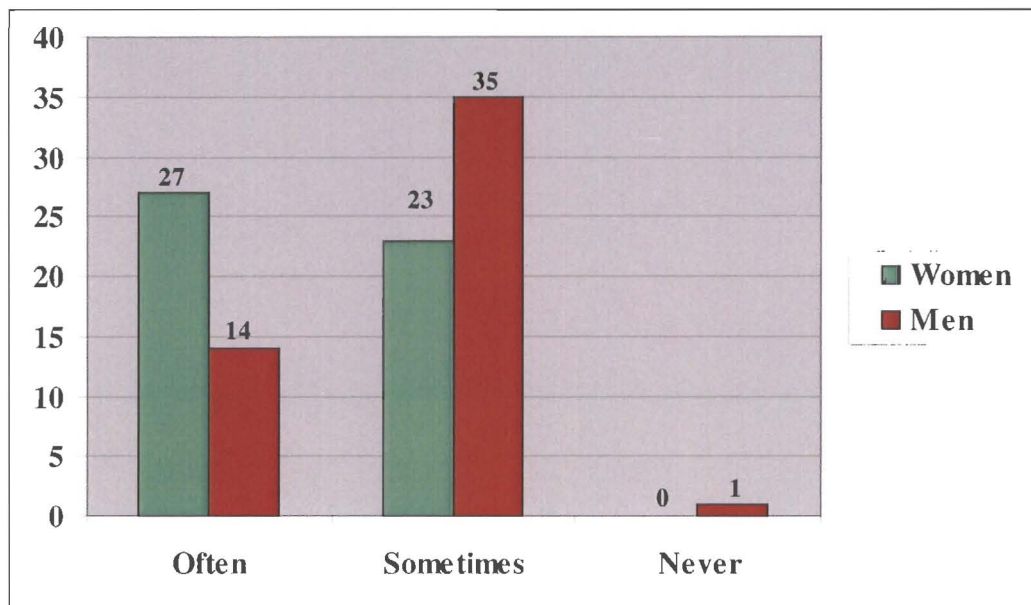
Item	Responses		
	N = 100		
	1	2	3
Happiness			
Nice to have children	1	4	95
Unique to relationship *	2	12	86
Children bring happiness	3	14	83
Well-being			
Completes relationship	6	35	59
Makes life complete	17	21	62
Goal to live for	5	32	63
Identity			
Obvious	4	47	49
Sign of grown-up	47	27	26
Nature	5	31	64
Parenthood			
Parental feelings	1	16	83
Parenthood is satisfying	1	16	83
To experience pregnancy	17	25	58
Social control			
Environment expects it	18	31	51
Others have children *	45	29	26
Avoid being outsider *	45	22	33
Continuity			
Continue name / tradition	9	23	68
Not to be alone when old *	15	49	36
To continue living	8	54	38

* Items more strongly enforced by women when compared to men ($p < 0.05$)

8.3.3. Reflection, Strength of Desire and Consensus between Partners

The degree of informants' reflection, measured through the frequency with which they thought about their parenthood motives, is shown in Figure 8.1. Women were significantly more likely than men to think often about why they wanted a child, while most men thought about it 'sometimes' ($p = 0.03$). Only one male informant said he never reflected on why he desired fertility.

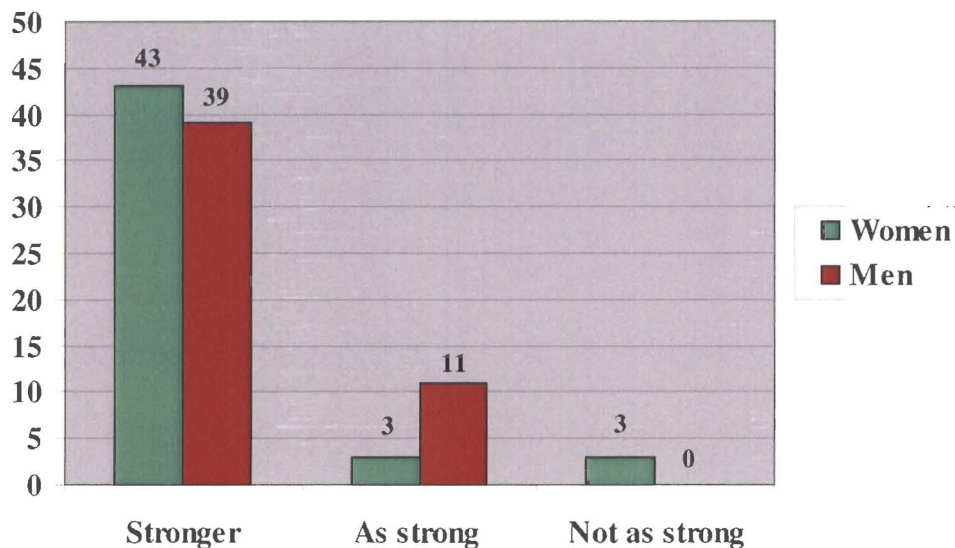
Figure 8.1. Time spent thinking about reasons for wanting a child



Women had a mean score of 4.8 ± 1.3 Standard Deviation (SD) on the six-point Likert scale for the question 'How strong is your wish for a child?' The mean score for male informants was significantly lower (4.3 ± 1.2 SD) when compared to women ($p = 0.02$). In contrast, no gender difference was observed on the second Likert scale ('How do you currently feel about the fact that you may never have a child/another child of your own?') with women having a mean score of 6.1 ± 1.7 SD and men a mean score of 5.9 ± 1.4 SD ($p = 0.57$). The majority of both men ($n = 29$) and women ($n = 36$) said that infertility was the worst thing that had ever happened to them.

Data analysis demonstrated poor consensus between partners in the interpretation of their strength of desire for a child compared to their spouses'. The majority of both women ($n = 43$) and men ($n = 39$) felt that their desire for a child was stronger than that of their partner. No man and only three women felt that their desire was less strong than their partner's (Figure 8.2).

Figure 8.2. Informants' assessment of own strength of desire when compared to that of their partner



8.3.4. Parenthood Motives and Strength of Desire

Several positive associations were observed between the six parenthood motives and strength of desire for a child (measured through the two Likert scales). As demonstrated in Table 8.5, among women five of the six parenthood motives showed a significant positive association with the first Likert scale ('How strong is your wish to have a child / another child?'). Happiness was the motive with the strongest association, while no association was found between this scale and continuity. In contrast, only happiness and social control showed a significant association with the second Likert scale ('How do you currently feel about the fact that you may never have a child/another child of your own?') among women.

Only two significant associations between parenthood motive and strength of desire were observed in the male data. The motive 'well-being' correlated significantly with the first Likert scale, while endorsement of the motive 'social control' showed a significant association with the second Likert scale. It is noteworthy that the correlation coefficient for social control almost reached statistical significance on the first scale.

Table 8.5. The association between parenthood motives and strength of desire for a child

Scale 1: 'How strong is your wish to have a child/another child?'

Scale 2: 'How do you currently feel about the fact that you may never have a child / another child?'

Parenthood Motive	Women N = 50		Men N = 50	
	Correlation Coefficients *	Correlation Coefficients *	Correlation Coefficients *	Correlation Coefficients *
	Scale 1	Scale 2	Scale 1	Scale 2
Happiness	0.495 **	0.556 **	0.240	0.135
Parenthood	0.413 **	0.128	0.114	0.154
Identity	0.305 **	0.190	0.244	0.054
Well-being	0.406 **	0.173	0.331 **	0.052
Continuity	0.076	0.145	0.183	0.134
Social control	0.289 **	0.319 **	0.286	0.305 **

* Correlation coefficients > 0.286 indicate a statistically significant association at level $p < 0.05$

** $p < 0.05$

8.4. DISCUSSION

This is the first study from South Africa in which parenthood motives were explored among infertile couples in a structured manner. The results demonstrated that the majority of informants endorsed the majority of parenthood motives and, therefore, had several motives for wanting a child. In addition, most participants expressed a strong

desire for a child. These findings indicate that parenthood is deeply rooted in our community and that children are wanted for many reasons. All but one of the informants spent at least some time reflecting on why they wanted a child. This observation is in keeping with the hypothesis that infertility leads to the manifestation of latent parenthood motives (van Balen and Trimbos-Kemper, 1995).

An analysis of the data by gender demonstrated that there were overall few differences between men and women. No gender difference was observed in the six parenthood motives. Four of the 18 individual items were endorsed with significantly greater frequency by women when compared to men. Two of these items belonged to the motive 'social control', but the difference was not sufficiently large to translate into a gender difference in the actual motive. This indicates a possible trend towards children having greater importance in the social domain of women when compared to men.

Women endorsed significantly more motives simultaneously when compared to men. Although this would suggest that women in our community may have more reasons (albeit not necessarily stronger reasons) for wanting a child, further research is required to confirm this finding.

Women, too, spent more time than men thinking about why they wanted a child and scored higher on one of the two Likert scales measuring strength of desire for a child. Men were less likely than women to answer 'I am willing to give absolutely everything' or 'I am willing to give a whole lot' to the question 'How strong is your wish to have a child / another child?' resulting in a lower mean score on this scale. The fact that a gender difference was observed on one but not the other Likert scale measuring strength of desire is difficult to explain. It is possible, as already outlined in chapter 6, that men gave 'socially correct' answers in order to present themselves favourably, although it is unlikely that they did so on one scale only (Berg et al., 1991; Greil, 1997).

The observation that men were less willing to give 'absolutely everything' or a 'whole lot' in order to have a child may, alternatively, be due to the fact that men perceived such

willingness as a poor solution to their childlessness, particularly when viewed against the backdrop of true poverty in our communities. In this context it must be considered that the male participants in this study were in all probability the head of their household and, in our largely patriarchal communities, probably charged with a greater responsibility of (financially) securing the home than their female partners.

This hypothesis highlights the recognised problem that research instruments which evaluate experiences and distress among infertile couples may be biased towards women. The reason for this bias is caused by a possible gender difference in the response to and expression of stress. Women often appear to develop psychological symptoms (i.e. anxiety and depression, the measurement of which is the goal of many standardised instruments). Men, in contrast, may react differently and, for example, may abuse alcohol or power, thereby demonstrating a stress reaction that may not be captured by standard instruments. As a consequence indices of female distress may be inflated in the literature, while the burden carried by men is perhaps insufficiently recognised (Berg et al., 1991).

Our findings indicate that men and women in this study wanted children for overall similar reasons and, probably, with similar intensity. Both men and women underestimated, however, their partner's strength of desire for a child. These observations corroborate some of the findings of the previous qualitative study involving male informants described in chapter 6. Although the current study focussed on reasons for wanting children and not on the consequences of infertility, like the previous study it supports the notion that the implications that involuntary childlessness carries for men have been underestimated. A better understanding of how gender shapes the experience of infertility is required, in order to counsel patients appropriately and to facilitate communication between partners.

In the original study by van Balen and Trimbos-Kemper (1995) the authors noted that the most frequently mentioned motives for parenthood may not always be the most important ones. The latter can be assessed through analysis of the association between parenthood motives and strength of desire for a child. In our study this analysis yielded a number of

interesting observations. For women 'happiness' was both the strongest and the most frequently endorsed motive thereby highlighting it as a central parenthood motive. Continuity was the only motive which did not correlate with strength of desire on any of the scales for both sexes and, therefore, appears to feature as the least important parenthood motive. In contrast, social control, although less frequently endorsed than some of the other motives, was positively associated with strength of desire on both scales for women and almost reached a significant association on both scales for men. Furthermore, social control was the only motive that correlated with strength of desire on the second Likert scale for both men and women. These findings suggest that participants who wanted parenthood for reasons of social control had a particularly strong desire for a child. It can be speculated that this association is generated by the fear or experience of negative social consequences of childlessness which resulted in infertility being 'life's worst experience'.

The analysis of the association between parenthood motives and desire for a child does, however, also raise questions. The overall lack of association in the male data is difficult to explain, as is the observation that the two Likert scales show different correlations with parenthood motives. Possible explanations for these findings include that men and women may construct their strength of desire for a child differently, that the two questions pertaining to the Likert scales measure different aspects or constructs of this desire, and/or that these questions may not be a perfect measure of the strength of the desire for parenthood. Possible limitations of the question 'How strong is your wish to have a child / another child?' in the setting of our study have already been discussed. The observation that this question may not be an altogether appropriate tool for the measurement of strength of desire for a child in our study cohort also highlights the difficulties of transforming emotions into a measurable quantity. This problem has been addressed in chapter 2.4.1. Further research in this area is required in order to ascertain what the strongest motives for parenthood are in our communities and why.

The use of an established research instrument offers the opportunity of comparing results with other studies which applied the same or a similar instrument. In the original study of

the parenthood-motivation list, van Balen and Trimbos-Kemper (1995) studied a cohort of 108 long-term infertile couples from the Netherlands. The respondents were considered to be representative of the Dutch population albeit with higher educational levels. None of the participants had children and about half of the informants were undergoing infertility treatment. For women the most frequently endorsed motives were happiness (84%), motherhood (68%) and well-being (56%). The strongest motives (as judged by the association between parenthood motives and strength of desire for a child) were motherhood and identity. Among men, the most frequently mentioned motives (happiness: 78%; well-being: 48%; fatherhood: 46%) also showed the strongest correlation with intensity of desire for a child. Continuity was endorsed by approximately one in four women and one in five men. Social control was an infrequent parenthood motive (women: 10%; men: 2%). When compared to our own findings, participants had lower mean scores on the Likert scale 'How strong is your wish to have a child / another child?' (Women: 4.09; men 3.79), and partners were more likely to perceive each other's strength of desire for a child correctly. The authors concluded that in the Netherlands motives reflecting parenthood as an expression of personal development (happiness and well-being) were more important than those pertaining to the interest of the group, continuity and heredity.

In a subsequent study from Belgium, Colpin et al. (1998) used the parenthood-motivation list in order to compare parenthood motives between IVF-mothers and mothers who had conceived naturally. Strength of desire for a child was not measured in this study. The authors demonstrated that parenthood motives were overall similar between the two groups. Happiness and well-being were the most frequently mentioned motives, and social control ranked lowest. Identity and motherhood featured more strongly among IVF- mothers. The authors argued that infertile women whose parenthood motives were closely linked to gender roles may be more likely to resort to assisted reproductive techniques than infertile women who prioritised other parenthood motives. Alternatively, it was considered that infertility threatened women's gender identity and that as a consequence a child would be considered more important in this domain when compared to naturally conceiving mothers.

In an earlier study Newton et al. (1992) applied a similar instrument, the Reason-for-Parenthood questionnaire (comprising 14 items, each rated on a three-point scale), together with other psychological self-report measures to approximately 1900 Canadian women and men undergoing assisted reproductive techniques. Men and women reported similar reasons for wanting a child. In keeping with the studies by van Balen and Trimbos-Kemper (1995) and Colpin et al. (1998), the leading parenthood motives fell within the domains of gender-role fulfilment, marital completion, and parent-role-longing. In addition, and in contrast to the above studies, alleviation of social pressure was also found to be an important motive. The results further demonstrated that seeking parenthood for reasons of gender-role fulfilment and for the alleviation of social pressure was associated with poorer adjustment to infertility when compared to men and women with other parenthood motives. The authors emphasised the importance of understanding parenthood motives in order to offer appropriate therapeutic interventions.

In Sweden, Lalos et al. (1985) used a different approach in a study on parenthood motives aimed at improving infertility management. The study cohort was diverse and comprised 30 infertile couples, 30 couples with ongoing pregnancies, 101 women presenting for antenatal care and 459 women applying for legal abortion (these latter women were asked what their parenthood motives would be if they were to have a child other than in the present situation). Following an open question relating to the wish for a child, respondents were asked to choose a maximum of five items from a set of 36 different reasons for parenthood. Parenthood motives were grouped into four broad categories: Philosophical motives (children representing immortality, the meaning of life and/ or God's wish), inter-personal motives (confirmation of the marital relationship), intra-psycho motives (comprising reasons of identity, to experience pregnancy, to gain independence, and to nurture a child) and socio-cultural motives (children conferring social status). The most frequently endorsed motives belonged to the inter-personal and intra-psycho domain while socio-cultural motives were rarely present. Parenthood motives were very similar between men and women and between the four groups, indicating that infertile women did not differ in their reasons for wanting a child from other women. The authors emphasised that further research on parenthood motives was

required and that information derived from this research would be of benefit in the counselling and treatment of infertile couples.

Further insight into parenthood motives was provided by recent study from the UK (Langdridge et al., 2000). The authors explored reasons for wanting a child among ten expectant couples who had no fertility problems, ten couples with primary infertility who were awaiting assisted reproductive techniques, and 14 couples who presented for donor insemination. Participants were recruited from two antenatal and two fertility clinics in Sheffield. Informants were presented with 24 items from which they were asked to select those which influenced their own desire for a child and to name any other reasons not among the pre-selected items. In addition, informants were asked to rank the reasons they selected in order of importance and to indicate, with the help of arrows, if they thought that one reason influenced another. The inter-relationship between reasons was evaluated through network analysis. The results demonstrated that in all three patient cohorts the triad 'give love', 'receive love' and 'enjoyment of a child' played a central role in the desire for a child. Moreover, the items within this triad were strongly interconnected indicating that these reasons were not perceived as being distinct from each other. In addition, all three groups emphasised the importance of becoming a family and of creating a child together, and these two items were again strongly inter-related. In contrast, none of the participants selected religion, social pressure, or enhancement of masculinity/femininity as a motive for parenthood. No significant gender difference was observed in the data.

Collectively, these studies from the industrialised world indicate that men and women wanted children for similar reasons, that infertile couples did not differ significantly in their parenthood motives from the general population, and that the most frequent reasons for wanting a child related to personal happiness and fulfilment and to dynamics within the conjugal relationship. With the exception of the Canadian study, social reasons were of minor importance.

As outlined in chapter 1.2 there is a paucity of studies from African countries in which parenthood motives have been systematically evaluated. With the exception of a study from Nigeria by Okonofua et al. (1997) insight into parenthood motives can only be derived indirectly from some qualitative studies on fertility and infertility. Studies from Mozambique, Nigeria, Chad, Gambia, Ghana and Ethiopia have documented that children play many important roles in the lives of their parents and their communities. These data have been presented in chapter 1.2.4. Briefly, children continue family lines, complete marriage, assist in domestic and subsistence related tasks, confer social status, secure land inheritance and property rights, offer security in old age, and ensure the proper conduct of funeral rituals, which are important in many African societies. In addition, they bring love and happiness to their families.

These reports support the results of this study indicating that in addition to motives relating to happiness and parenthood many other factors from the domain of culture, society, continuity, and heredity remain central in the wish of men and women to have children. Parenthood therefore appears to have more and, arguably, deeper roots in African communities when compared to industrialised countries. These roots are a reflection of the value and role of children in African communities and contribute to understanding why men and women want to have children, why fertility rates remain high in many areas in Africa, and why infertility is a dreaded condition.

The parenthood-motivation list has not been formally validated in South Africa, and this is a limitation of our study. Our findings have to be interpreted in this context. The fact that a detailed and stringent statistical analysis demonstrated that our data could be applied to the research instrument is, however, encouraging. This would suggest that the parenthood motives *per se* are constructed similarly in South Africa and the Netherlands, although the frequency with which they are endorsed differs between the two countries. Further studies involving larger cohorts and different groups of informants are now required in order to expand the findings derived from this first study on parenthood motives in South Africa. The results of this research should inform the counselling and management of couples suffering from involuntary childlessness.

On a much larger scale the understanding of parenthood motives may offer important insight into human reproductive behaviour. One of the questions that arises is how the desire for a child, as one of the driving forces for procreation, relates to the HIV/AIDS epidemic which represents an opposing force to human reproduction in African countries. This question is addressed in the following two chapters.

8.5. SUMMARY

This study explored parenthood motives and strength of desire for a child among 50 couples suffering from infertility. The parenthood-motivation list (a standardised instrument developed in the Netherlands) was used and piloted. The results demonstrated that men and women expressed a strong desire for a child and endorsed a wide range of parenthood motives. Furthermore, men and women had similar reasons for wanting a child but underestimated their partner's strength of desire for a child when compared to their own.

CHAPTER 9

HIV-NEGATIVE INFERTILE COUPLES: THEIR KNOWLEDGE OF HIV/AIDS AND THEIR ATTITUDES TOWARDS REPRODUCTION IN HIV-POSITIVE COUPLES

9.1 INTRODUCTION

The HIV/AIDS pandemic has created a strong opposing force to the high demand on fertility in Africa. As outlined in chapter 1.2.7 it exerts this effect by reducing fecundity rates in people with HIV/AIDS and by creating a context in which sexual abstinence or 'safe sex' is considered to be responsible behaviour of those infected. Despite this negative impact on fertility, HIV-infected couples continue to have children, and some of those suffering from involuntary childlessness seek help from reproductive health services – often unsuccessfully.

The reasons why HIV infection has been deemed a contra-indication to infertility treatment have been discussed in chapter 1.2.7.3. Briefly, these include the risk of vertical transmission to the baby, the risk of HIV transmission to a non-infected partner, concerns related to morbidity and mortality in the prospective parent(s), as well as the concern of cross-contamination in the gamete laboratory (Ryan, 2001; Ethics Committee of the American Society of Reproductive Medicine, 2002). The advent of anti-retroviral treatment has modified these risks and in developed countries HIV-infected individuals are gradually gaining better access to infertility treatment (Englert et al., 2001; Lyerly and Anderson, 2001; Frodsham et al., 2004; Frodsham et al., 2006). Due to the overall restricted access to anti-retroviral treatment in most developing countries the barriers to infertility care have, however, largely persisted in these areas.

At the time of this study, highly active anti-retroviral therapy (HAART) was not available to patients accessing health care in the public sector, and HIV-positive couples were excluded from infertility interventions in our unit. The growing understanding of the importance of fertility derived from the research described in the previous chapters highlighted the need to develop an approach to the management of HIV-infected, infertile people. This approach had to be based, among other factors, on an understanding of the reality of infertility and HIV and of the reasons as to why HIV-infected, infertile couples wished to have children. Generally speaking this understanding was lacking, and little was known about how men and women from our communities experienced and constructed infertility and HIV infection. In addition, no studies could be identified which had addressed this problem in other African countries.

Two studies were undertaken to improve our understanding of infertility and HIV in our community. In one of the studies in-depth interviews were conducted with HIV-infected, infertile men and women, and these data are presented in the next chapter. Here the second part of the study described in chapter 8 is presented. In this second part we explored the association between motives for parenthood and attitudes towards fertility and infertility treatment in HIV-infected couples. The interest in assessing this association was based on the previous observation that not only the child, but fertility in itself was valued and important in our communities. In some instances this value of fertility appeared to be equal or arguably greater than the value and importance attached to the child. The observation that children were often conceived for reasons related to parental status and well-being rather than in their own right was also made in a study from Zimbabwe which explored the meaning and consequences of reproductive failure (Runganga et al., 2001).

Based on these observations, we postulated that an association existed between parenthood motives and a couple's reproductive decisions in the presence of HIV infection. We hypothesized that in a community, where treatment options for HIV/AIDS were limited, people who wanted children for the sake of happiness, would perhaps decide against reproduction in the presence of HIV infection, while those who sought

parenthood for reasons of social status and gender identity might wish to conceive irrespective of HIV.

The ideal study cohort for testing this hypothesis would consist of HIV-infected, infertile individuals. Currently we do not have accurate data on the prevalence of HIV among patients who access our clinic, but it is estimated that 5-10% of newly referred couples test positive for HIV at our clinic every month (2-4 couples per month). Based on this rate and on the fact that we anticipated that several couples would decline to participate in the study, we did not expect that a cohort sufficiently large for a quantitative analysis could be recruited. A decision was therefore taken to test the hypothesis in HIV-negative, infertile individuals. This required that real-life decisions (whether or not to attempt reproduction despite HIV infection) had to be substituted with participants' attitudes towards fertility and infertility management in HIV-positive individuals. As a secondary aim of this study, participants' knowledge of HIV/AIDS and their understanding of possible risks in pregnancy were evaluated.

9.2. PATIENTS AND METHODS

The study cohort and methodology have been presented in chapter 8. Briefly, 50 HIV-negative, infertile couples were recruited immediately prior to their second medical consultation at the infertility clinic, and a three-part questionnaire was administered to all participants. The first two parts contained socio-demographic questions and the parenthood-motivation list (chapter 8). The third part of the questionnaire, which was designed for the purpose of this study and the results of which are presented in this chapter, captured data on the knowledge of HIV/AIDS, including possible risks in pregnancy, and assessed participant's attitudes towards fertility and infertility treatment in HIV-infected people. Participants' attitudes towards three possible scenarios were explored: (1) Spontaneous conception in couples in whom one or both partners were HIV-positive, (2) infertility treatment in HIV-positive, sero-discordant couples and (3)

infertility treatment in HIV-positive, sero-concordant couples (see Appendix D). The responses to these scenarios are referred to as ‘attitudes’ in the text.

Knowledge of HIV/AIDS was evaluated through an open-ended question. All other questions were closed questions with four possible answers (‘yes’, ‘no’, ‘that depends’, ‘I don’t know’). If the answer ‘that depends’ was chosen, informants were asked to elaborate. For the three remaining answers any additional comments or explanations that were freely forwarded were documented, but respondents were not asked to explain their answers further. The decision to restrict the extent of qualitative data collection was based on the fact that the study was intended to capture predominantly quantitative data. In addition, concern existed that excessive data capture would induce questionnaire fatigue in the respondent and possibly reduce willingness of the partner to be interviewed.

9.2.1. Statistical Analysis

The paired t-statistic was used to test for significance of differences between male and female informants. In order to examine the relationship between parenthood motives/strength of desire for a child and attitudes, one-way ANOVA was applied. For this analysis the factor scores for the six parenthood motives and the scores of the two Likert scales measuring strength of desire for a child were used as response variables and the attitudes as a group or categorical variable. In a second analysis of the data only ‘yes’ and ‘no’ replies of attitudes were considered, while the answers ‘I do not know’ and ‘that depends’ were excluded. These analyses were conducted separately for male and female informants to accommodate a possible gender difference in the data.

Lastly, the relationship between the 18 individual items of the parenthood motivation list and attitudes were explored. Here two-way contingency tables and the chi-square test were used to assess statistical significance of the association. Male and female data were again analysed separately. No sub-analysis was conducted in which only ‘yes’ and ‘no’ replies of attitudes were considered. This decision was taken as such a sub-analysis would have resulted in very small numbers, thereby preventing a meaningful interpretation of the data.

9.3. RESULTS

The demographic characteristics of the study cohort have been presented in chapter 8 (Table 8.2).

9.3.1. Knowledge of HIV/AIDS

Ten informants (five men and five women) said they knew their HIV status before coming to the infertility clinic, and of these two were married to each other. The other 90 patients were unaware of their HIV status until just prior to the interview.

The single commonest feature mentioned of HIV /AIDS was its transmissibility. All but nine informants referred to modes of HIV/AIDS transmission, which included coitus (mentioned by all 91 informants who referred to HIV transmission), blood (through transfusion or by handling infected blood), needles (through lack of sterility and/or drug abuse) and breast milk. One participant mentioned homosexuality as a risk factor. Several participants (n = 34) also spoke about strategies to prevent transmission, which included the use of condoms, the importance of having a single (faithful) partner, and avoiding contact with blood.

The next commonest features described included the deadliness of the disease (n = 43) and the absence of cure (n = 40). Only ten patients volunteered knowledge outside this framework. These latter respondents spoke about weight loss, depression and stigmatisation secondary to infection, the risk of vertical transmission, the need to distinguish between HIV and AIDS, and the importance of a healthy life style in prolonging the disease free interval. Men and women had overall the same degree of knowledge, and no gender difference was evident in the data.

9.3.2. Attitudes towards Fertility and Infertility Treatment in HIV-Infected Couples

Table 9.1 summarises the informants' attitudes towards fertility and infertility treatment of HIV-infected couples. It also presents data pertaining to the last item of the questionnaire in which informants were asked whether they themselves would persist with infertility treatment should they and/or their partner have tested HIV-positive. No gender difference was observed in any of the data, and male and female responses are therefore presented jointly.

Table 9.1. Attitudes to spontaneous and treatment induced fertility in HIV-positive couples

* Question	Answers N = 100				
	Yes	No	Depends	Don't know	** Comments
Should HIV-positive couples have children?	27	43	20	10	64
Should HIV-discordant couples be offered infertility treatment?	19	47	25	9	61
Should HIV-concordant couples be offered infertility treatment?	5	88	3	4	70
Would you continue infertility treatment if you/your partner had tested HIV positive?	19	74	4	3	49

* For exact phrasing of question see Appendix D

** Comments = number of participants who gave additional comments to their answer

Just under half of all participants were against HIV- infected people having children and opposed the idea of offering infertility treatment to HIV-positive, sero-discordant couples. The large majority (n = 88) opposed infertility treatment in HIV-positive, sero-

concordant couples. Three out of four participants felt that they themselves would abandon infertility treatment if they and/or their partner had tested positive.

Approximately two thirds of informants elaborated on their answers (Table 9.1). Analysis of these qualitative data demonstrated that the reasons that respondents volunteered in support of their answers essentially did not differ between the three scenarios.

The dominant reasons forwarded in support of spontaneous conception and infertility treatment were the couples' right to have children and/or the importance of experiencing pregnancy and childbirth. Only four respondents based their positive attitude on the fact that drugs could prevent vertical transmission. The importance of fertility is reflected in the words of this woman who said: "Yes, they should be helped... because of the desperation...even if the child can only live for two months... because it is very important for a woman to know that she can have a child". The same woman opposed, however, infertility treatment in sero-concordant couples because of the expected mortality in both parents and offspring.

Informants who answered 'that depends' felt that consideration should be given to how important it was for a couple to have a child, whether the couple already had children, the accessibility of anti-retroviral therapy, and the stage of the disease. Three informants said their attitude towards spontaneous fertility depended on which partner was infected (with negative attitudes towards fertility in HIV-positive women), and many more considered this an important factor in deciding whether infertility treatment should be offered to HIV sero-discordant couples. Three respondents said that treatment was dependent on hospital resources.

The reasons for opposing fertility and also infertility treatment centred predominantly on the perceived risks of HIV/AIDS to the offspring (illness, early demise and /or lack of proper care due to parental illness or death), the risk of HIV infection of a non-infected partner, and the likelihood of death of one or both prospective parents. In addition, five respondents opposed reproduction in HIV-positive couples as this would increase the

number of people with HIV/AIDS. Several others felt that the hospitals did not have the resources to offer infertility treatment to HIV-positive couples or that such treatment would constitute a waste of resources. A few participants added that infertility treatment should be reserved for people who were able to give something back to the community (implying that HIV-infected couples would or could not contribute). Eight informants recommended that HIV-infected people should rather adopt a child.

The final item in the questionnaire asked participants whether they would have persisted with infertility treatment should they and/or their partners have tested positive (Table 9.1). The explanatory comments were in keeping with those forwarded in the previous scenarios and included the wish to experience pregnancy and childbirth, the need to consider which partner was positive and whether treatment could be accessed, and the concern that HIV/AIDS would lead to illness and death. One of the informants appeared to summarise these concerns by saying “No, because this result [HIV-positive status] will change the whole plan... even though I do not have a child... I think I would have to give up”. A female informant, who explained that she was “desperate” to conceive, expressed a different view. “I don’t worry about HIV, my worry is a baby” she said.

9.3.3. Perceived Risks of HIV/AIDS in Pregnancy

Subsequent to the questions capturing attitudes towards fertility and infertility treatment, all respondents were asked whether HIV/AIDS presented a risk for pregnant women and/or their offspring. The findings relating to these questions are summarised in Table 9.2. Men and women did not differ in their responses. The majority of informants ($n = 82$) felt that HIV/AIDS posed a threat to the baby, and just over half of the respondents considered it potentially dangerous for the mother. Approximately one third of the cohort said they did not know whether HIV/AIDS posed maternal risks.

The commonest explanation forwarded for a perceived increase in maternal risk was that the woman would get “sick” and/or contract infections, and many added that this happened “easily” or “most of the time”. Ten respondents felt that HIV-positive pregnant

women would suffer from fatigue or weakness, and some felt that women failed to recover from the delivery and that operative wounds would not heal. Six participants said that pregnancy could result in the death of the woman. Other risks mentioned sporadically included, among others, tuberculosis, stress, weight loss, haemorrhage and preterm labour. The overall negative impact of HIV/AIDS on maternal health is reflected in the words of this woman who said: “Women who are HIV-positive will be sicker than normal pregnant women, they get more infections and they suffer from more stress because of their worry about their health and the risk of infecting their baby.

Table 9.2. Perceptions of HIV/AIDS-related risks in pregnancy

Question *	Answers N = 100				
	Yes	No	Depends	Don't know	Comments **
Is pregnancy more dangerous for women who are HIV-positive than for those who are not?	49	10	5	36	59
Is HIV infection in the mother dangerous for the baby?	82	7	9	2	97

* For exact phrasing of question see Appendix D
 ** Comments = number of participants who gave additional comments to their answer

In contrast, ten participants did not perceive pregnancy to carry additional dangers for HIV-positive women. Three of them explained that many pregnancy complications existed other than HIV. The other seven did not elaborate on their answer. Those who answered ‘that depends’ attached importance to the stage of disease and the general lifestyle of the woman.

Vertical transmission was the leading reason as to why HIV/AIDS was seen as a risk to the offspring. Some respondents stated this risk as a fact (“The baby *will* be born with HIV/AIDS”) while others raised it as a possibility (“The baby *may* get infected”). Forty

six respondents mentioned infant death as a possible outcome. Poor fetal/neonatal growth and the risk of prematurity was listed by several others, while miscellaneous concerns included mental retardation, slow achievement of milestones, a high cost of care (because of the need for medical treatment), and orphanhood. These concerns are illustrated in the words of this informant who said: “The child will get sick and may not make it... it will not be the child you want it to be. In most cases the mother dies, and somebody else will take over [care] and the child suffers.”

Those who answered ‘that depends’ or who felt that HIV/AIDS posed no risks to the baby based their answers on the fact that medical interventions would, if available, prevent mother to child transmission.

9.3.4. Association between Parenthood Motives and Attitudes towards Fertility and Infertility Treatment

The statistical analysis of the relationship between parenthood motives/strength of desire for a child and attitudes towards fertility and infertility treatment did not reveal any significant association between these variables. Men and women who opposed reproduction in HIV-positive couples appeared to have similar parenthood motives and the same desire for a child as those who were supportive or who considered it justified under certain circumstances. Similarly, no association between these variables could be detected if only yes/no answers pertaining to attitudes were considered in the analysis.

This lack of association led us to explore whether the attitudes were influenced by the participants’ knowledge of HIV-related risks in pregnancy. The same statistical approach for the analysis of the relationship was utilised (one-way ANOVA), but again no significant association between the data could be detected.

The last analysis explored the relationship between the 18 individual items of the parenthood-motivation list and attitudes. There was no significant association between endorsement of the 18 items and attitudes in the majority of the relationships analysed with the exception of two items in men and one item in women. Among both male and

female respondents a significant association was found between a supportive attitude towards offering infertility treatment to HIV-positive, sero-discordant couples and the endorsement of the item 'it is the nature of man/woman' (women: $p=0.03$; men: $p=0.003$). In addition, men's endorsement of the item 'to have a unique relationship with the child' was positively associated with a supportive attitude towards spontaneous fertility in HIV-positive couples ($p=0.04$).

9.4. DISCUSSION

This study explored knowledge about HIV and reproduction and attitudes towards fertility and treatment of infertility in the presence of HIV in a cohort of HIV-negative, infertile couples. The findings generated by this study expand our existing understanding of the construct of HIV/AIDS in our community.

The observation that among the informants, all of whom were actively trying to conceive, only one couple knew that both partners were HIV-negative is concerning. This result cannot be attributed to ignorance of the risks of infection or the seriousness of the disease as all informants had an adequate knowledge of HIV/AIDS. No further conclusions can, however, be drawn as this study did not aim to explore how individuals constructed their own risk for contracting HIV and what barriers existed for HIV testing.

HIV/AIDS was, in the first instance, described as a transmissible disease. Other features included the deadliness of the infection and the fact that it could not be cured. Upon questioning, most informants were aware of the risks of vertical transmission in pregnancy and the poor prognosis that HIV infection carried for the neonate. In comparison, maternal risks were less well perceived. This latter finding is in stark contrast with the latest report on the Confidential Enquiries into Maternal Deaths in South Africa for the triennium 1999-2001 (Pattinson, 2002). According to this report the Maternal Mortality Ratio (MMR) for the triennium was estimated at 175-200 deaths per 100 000 live births (the current health information system does not allow for the accurate

recording of all live births, and the MMR can, therefore, only be estimated and not calculated). AIDS was the commonest cause of maternal mortality and accounted for 31.4% of the reported deaths. Many women died from respiratory failure secondary to pneumonia and/or tuberculosis. The report also noted that the MMR had, in all likelihood, increased from 1998 when the first confidential enquiry was conducted. This increase was attributed to HIV/AIDS.

The findings relating to knowledge need to be interpreted with caution, since we did not conduct an in-depth enquiry into how participants understood and constructed HIV/AIDS. Our results are, however, largely in keeping with other studies from South Africa. Campbell (1997) conducted in-depth interviews with men working on a gold mine in Johannesburg, South Africa. The dominant concept of HIV/AIDS was that of a sexually transmitted disease, which could be prevented through the use of condoms and which was incurable once contracted. Despite extensive efforts by the mine managers to further educate labourers about HIV/AIDS, few respondents had knowledge outside this framework.

Similar results were reported from a semi-quantitative study conducted in Cape Town in which Blecher et al. (1995) evaluated AIDS-related knowledge among 306 patients attending clinics for sexually transmitted disease. The majority of participants constructed AIDS as a fatal illness transmissible by coitus, but more in-depth knowledge was often lacking. In contrast, Friedland et al. (1991) reported that university students in Johannesburg were well informed about HIV/AIDS. It is likely that the higher degree of knowledge in this study, when compared to the other studies from South Africa, is related to the higher level of education among the informants. The authors noted with concern that good knowledge had little impact on the students' sexual behaviour.

The fact that we did not elicit any traditional beliefs about HIV/AIDS was surprising given the fact that such beliefs were captured in the context of infertility (chapter 3 and chapter 6). It is possible that the research methodology (structured questionnaire) limited the collection of data in this regard. The difficulty of eliciting information on traditional

beliefs in biomedical research has been addressed in chapter 3. According to Kalichman and Simbayi (2004) traditional beliefs relating to HIV/AIDS exist in our communities. The authors documented that 11% of youths living in a poor, black community in Cape Town believed that AIDS was caused by spirits and supernatural forces, and a further 21% expressed uncertainty in this regard. Traditional beliefs were positively associated with stigmatising attitudes. The existence of traditional beliefs relating to HIV/AIDS and the fact that the construct of HIV/AIDS as a supernatural disease contributes to stigmatisation has also been reported from Zimbabwe, Uganda, and Ghana (Scott and Mercer, 1994; Withell, 2000; Mill, 2003). HIV/AIDS-related stigma is discussed further in the following chapter.

Nearly half of all informants in this study opposed pregnancy in HIV-infected people and infertility treatment in HIV-positive, sero-discordant couples. Only five participants were in favour of assisting couples in whom both partners were HIV-positive. This largely negative attitude to reproduction was an unexpected finding of our study. We had anticipated that a cohort of men and women who themselves were eager, if not desperate, to conceive and among whom many described infertility as 'life's worst experience' would be largely supportive of infertility treatment of others. Our results demonstrated, however, that there was no association between informants' own parenthood motives and desire for a child and their attitudes to fertility/infertility treatment. It therefore appears that these variables are independent of each other.

The positive association between endorsement of the item 'it is the nature of man/woman' and a supportive attitude towards infertility treatment in HIV-positive, sero-discordant couples is difficult to explain and needs to be interpreted with caution. It would appear from this analysis that men and women who strongly believe in the natural drive for having children are in favour of infertility management in HIV-positive couples, provided one partner is HIV-negative. This interpretation makes it difficult to explain why endorsement of the same item was not associated with a supportive attitude towards spontaneous fertility in the presence of HIV infection. Similarly, the relevance of the association between the item 'to have a unique relationship with the child' and a positive

attitude of men towards spontaneous conception in HIV-positive people is not evident at this stage. Further research is required to explore the meaning and practical relevance of these findings.

According to the explanatory comments, the negative attitudes towards fertility/ infertility treatment in HIV-infected individuals were predominantly shaped by the pessimistic outlook of HIV/AIDS in our community. This overwhelmingly negative outlook is a reflection of the devastating course that the HIV/AIDS pandemic has taken in South Africa. Although the pandemic reached South Africa later than many of the other sub-Saharan countries, the country has to date the highest number of HIV-infected people in the world. In 2005 an estimated 5.5 million people were living with HIV and 320 000 had died from the disease in this year (UNAIDS, 2005). According to a recent UNAIDS epidemic update there is no convincing evidence that the epidemic is declining in South Africa (UNAIDS, 2005). In a report on burden of disease estimates for South Africa, Bradshaw et al. (2003) predicted that in the absence of treatment interventions, and assuming that the profile of other causes of death did not change, HIV/AIDS would account for 75% of premature deaths by the year 2010.

It is to be hoped that the advent of anti-retroviral therapy in conjunction with comprehensive health strategies will reduce HIV/AIDS related mortality and result in a decline in HIV prevalence in the future. The South African Government approved the use of anti-retroviral therapy in the public health sector in 2003. Despite the allocation of considerable government funds to HIV/AIDS programmes, the rollout of anti-retroviral therapy has, however, been comparatively slow and time consuming, based, among other factors, on the lack of human resources (Cooper et al., 2004; UNAIDS, 2005).

The rapid spread of HIV/AIDS among adults has been paralleled by rising numbers of HIV-infected children and AIDS orphans. Among the 5.5 million people living with HIV/AIDS in the year 2005 in South Africa 240 000 were children, and a further 1.2 million were orphaned by the disease (UNAIDS, 2005). Neonatal and paediatric HIV infection places a high burden on health resources (Jeena et al., 1999).

Behind these concerning statistics is the considerable suffering of infected individuals, their families and their communities. It appears that this reality was captured in our qualitative data and that it motivated many of our informants to reject reproduction in HIV-infected people. To what extent this reality has since changed with the advent of HAART and an improved public health infrastructure for the management of HIV/AIDS epidemic, and how this influences attitudes towards fertility in the presence of HIV requires further research.

It must be noted that not all informants opposed fertility and infertility management in HIV-infected individuals. One in four informants was supportive of reproduction in HIV-positive couples, and approximately one in five respondents felt that HIV-positive, sero-discordant couples should be given access to infertility treatment. Scientifically, the advent of anti-retroviral therapy has been one of the leading arguments in favour of fertility and infertility treatment in HIV-positive couples. Interestingly, this argument was not commonly forwarded by study participants. Instead, the supportive attitudes towards fertility and infertility treatment were predominantly based on the importance of fertility and on a person's right to have children. We can hypothesize that due to the limited access to anti-retroviral therapy in our community, participants may not have considered such therapy as a realistic intervention. Alternatively, these informants may have believed that the central reason for supporting reproduction in HIV-positive couples was the importance of fertility and children and not the availability of anti-retroviral therapy.

A few studies have evaluated attitudes towards fertility in HIV-positive people, but most of these involved health care workers. In South Africa, de Bruyn (2004) interviewed eight key informants from various organisations working with HIV/AIDS in order to explore issues relating to HIV and fertility. According to these informants, community members and health care workers often believed that HIV-positive women who became pregnant were irresponsible, and at times these women were harassed and ostracised. The advent of anti-retroviral therapy did not appear to have altered this negative attitude. In studies from Brazil and Switzerland, HIV-positive men and women reported that health care

professionals provided inadequate support in matters relating to reproduction (Paiva et al., 2003; Panozzo et al., 2003). These studies are discussed further in the next chapter.

The results of our study indicate that the prevailing attitude of HIV-negative, infertile individuals towards reproduction in the presence of HIV infection is negative. This attitude may be even more pronounced among those who have never experienced the distress of involuntary childlessness. It is likely that these attitudes shape the reality of living with HIV/AIDS in our communities and, when violated, may contribute to HIV-related stigma. Laryea and Gien (1993) have previously reported that fears and negative attitudes held by the general public create many difficulties for people suffering from HIV/AIDS. The authors conducted a qualitative study among HIV-positive informants in Newfoundland. Although issues related to fertility were not addressed in this study, the narratives highlighted how negative attitudes among the public led to rejection, stigmatisation, and social isolation of HIV-positive individuals (Laryea and Gien, 1993).

The largely negative attitude towards reproduction in the setting of HIV-infection was upheld by most of the informants when asked how they themselves would decide about infertility management in the presence of HIV. This finding only reflects how informants thought they would react and does not represent real-life decisions. It is likely that a discrepancy exists between the two. It can be hypothesized that a known negative HIV status may allow an individual to identify him/herself with what is perceived to be moral and responsible behaviour (i.e. not to reproduce in the presence of HIV). In contrast, the reality of HIV-infection associated with the despair about childlessness may result in a different decision-making process. The desire for children among infertile, HIV-positive men and women, and their requests for infertility management are the subject of the next chapter.

9.5. SUMMARY

This study explored in a cohort of HIV-negative, infertile couples' knowledge of HIV/AIDS, attitudes towards spontaneous or treatment induced fertility in HIV-infected couples, and the association between informants' attitudes and their parenthood motives. Our findings indicated that men and women had a basic but adequate knowledge of HIV/AIDS, except that the maternal risks in pregnancy were possibly underestimated. The respondents were largely opposed to fertility and infertility treatment in HIV-infected individuals. No association could be detected between the participants' own motives for parenthood or strength of desire for a child and their attitudes towards fertility in HIV-infected individuals.

CHAPTER 10

“I AM STILL HOPING, BECAUSE I AM STILL ALIVE” – EXPERIENCES AND PERSPECTIVES OF HIV-POSITIVE, INFERTILE MEN AND WOMEN

10.1. INTRODUCTION

Following the onset of the HIV/AIDS pandemic in South Africa approximately two decades ago, routine HIV screening was introduced at our infertility clinic and HIV-positive couples were excluded from infertility investigations and treatment. Many infertility centres in other parts of the world have followed a similar policy (Marcus et al., 2000; Apoola et al., 2001; Sauer, 2006). Whether or not it is justified to withhold infertility treatment from HIV-infected couples has been the subject of extensive debates as outlined in chapter 1.2.7. What has been inadequately explored, however, is the question of what happens to the individuals and couples who test HIV-positive when they seek help for infertility, and who are often, at least in most developing countries, left with no hope of treatment for either infertility or HIV/AIDS.

This study was undertaken in order to explore the experiences of men and women who suffered from couple infertility and who had been declined infertility treatment at our clinic, because they and/or their partner were HIV-positive. Understanding these experiences is important for the appropriate counselling of infertile, HIV-infected men and women who seek assistance from the biomedical health sector.

10.2. METHODS

Twenty interviews were planned with male and female informants who had presented to our clinic with the problem of infertility. The criteria for inclusion were HIV infection in the informant and/or the partner and, during the first phase of data collection (see below) his/her ability to converse in English, Afrikaans, or Xhosa. During the second phase only informants who could communicate in English were recruited. Both partners were encouraged to participate, but respondents were recruited alone if their partner was unwilling or unavailable to enter the study.

The process of HIV screening at our clinic has been described in chapter 2.2.1. Prospective participants were identified in a confidential register in which members of the nursing staff recorded the hospital number of patients who had tested HIV-positive at our clinic. Patients were invited telephonically (minimum of two attempts) or in writing (one attempt) to participate in the study. Confidentiality was maintained at all times. In the process of informed consent emphasis was given to the fact that participation in this study was not associated with access to infertility interventions.

Semi-structured, in-depth interviews were undertaken and analysed as outlined in chapter 2. All interviews were conducted at the infertility clinic, and respondents were reimbursed for the cost of travel to the hospital. Couples where both partners were willing to participate were interviewed separately but in the same setting, and partners were given no opportunity to communicate with each other until both interviews were completed. The interview guide of this study is outlined in Appendix E. The themes included experiences related to infertility, to HIV counselling and testing, and to the diagnosis of HIV infection. The impact that these experiences had on the marital relationship and on the wish for a child was explored. In addition, informants' knowledge regarding the risks of HIV infection in pregnancy was discussed. Respondents who

experienced high levels of distress and who raised health-related issues during the interview were counselled immediately after the interview and appropriately referred.

Two waves of data collection occurred. Seven interviews were conducted between July and November 2004 by a multilingual professional nurse. She resigned from her position as research sister in December 2004 for reasons unrelated to the study. Efforts to find a suitable replacement remained unsuccessful for several months. This prompted the decision to engage the principal researcher in the data collection and further interviews were conducted between April and June 2005. These latter interviews were conducted in English.

Operationally defined verbal counting was applied in this study as follows: The term 'few' refers to more than one but less than five respondents. 'Some' and 'several' denotes the range between five and nine informants with some referring to the lower numbers and several to the upper numbers within this range. Ten to twelve participants are referred to as 'many', and the terms 'most' and 'the majority' are used synonymously for any group of 13 or more informants.

10.3. RESULTS

10.3.1. Recruitment

A total of 17 interviews were conducted. The informants comprised six couples (12 interviews) as well as three women and two men who participated without their partner. Reasons for participating alone included separation following the diagnosis of HIV infection ($n = 3$) and unwillingness of the partner to be interviewed ($n = 2$).

The desired number of twenty interviews could not be reached. Several patients recorded in the register could not be contacted, and eight couples refused to participate. Three of

them gave reasons for their refusal which included lack of time, the unwillingness to discuss the issues, and anger at being denied infertility treatment.

The decision not to extend the period of recruitment was based on the fact that the context of HIV/AIDS in our community was changing due to attempts within the public health care sector to offer anti-retroviral therapy to selected patients. It was felt that the advent of anti-retroviral therapy altered the common background against which the interviews had been conducted. This background was characterised by the absence of anti-retroviral therapy in the public health sector, except for the prevention of mother-to-child transmission. The new context created by the advent of anti-retroviral therapy requires to be explored, but was not the focus of this study.

10.3.2. Demographic Information

The HIV status of the informants and that of their partner is outlined in Table 10.1. Fifteen respondents were HIV-positive. The other two informants (one woman and one man) participated with their HIV-positive partner.

Participants were between the age of 28 and 41 years. At the time of the diagnosis of HIV infection, one couple and two female informants were living in common law relationships. The remaining 14 informants were married. Six participants had no live child, and 15 had no live child in union. One couple had a child who was born prior to marriage. Another two women and seven men had at least one live child from previous relationships. The reported duration of infertility ranged from one to five years. All informants spoke Xhosa as their home language. Respondents had nine or more years of schooling. Two participants had entered tertiary education, but had subsequently discontinued their studies.

Table 10.1. HIV status, relationship status and the wish for a child among informants

Note: Information in italics refers to partners not participating in the study

Informant Number	HIV Status	Ongoing Relationship	Wishing for a Child	Trying to Conceive Spontaneously
1a	positive	Yes	Yes	Yes
1b	negative	Yes	Yes	Yes
2a	negative	Yes	Yes	No
2b	positive	Yes	Yes	No
3a	<i>negative</i>	-	-	-
3b	positive	Yes	Yes	Yes
4a	positive	Yes	Yes	No
4b	positive	Yes	Yes	No
5a	<i>negative</i>	-	-	-
5b	positive	No	No	No
6a	positive	No	No	No
6b	<i>negative</i>	-	-	-
7a	positive	No	No	No
7b	<i>unknown</i>	-	-	-
8a	positive	Yes	Yes	No
8b	positive	Yes	Yes	No
9a	positive	Yes	Yes	Yes
9b	<i>positive</i>	-	-	-
10a	positive	Yes	Yes	Yes
10b	positive	Yes	Yes	Yes
11a	positive	Yes	Yes	Yes
11b	positive	Yes	Yes	Yes

a = female informant
b = male informant

10.3.3. Experiences Related to Infertility

At the beginning of the interview respondents were asked to outline their experiences related to their inability to conceive. The majority of informants described infertility as a very negative experience, and many used the terms “painful”, “sad” and “devastating”. Three women cried in response to the question.

For four of the male informants the worry about their partner’s well-being appeared to shape their experience of infertility. These men expressed their own sadness but indicated that the experience was worse for their wife, mainly because of the scorn and insults they were subjected to by others. This social pressure to reproduce was also described by two female informants one of whom simply said: “I will be married, so it [not falling pregnant] will be a disgrace”. In contrast, three other women said that their family and friends had been supportive towards their inability to conceive. The remainder did not comment on the social experiences of infertility and were not further probed for information.

10.3.4. The HIV Test

One woman was diagnosed with HIV during an episode of tuberculosis six years earlier. All other respondents received the information about their positive HIV status from our infertility clinic.

Eight informants said that they were not given enough information at the time of the pre-test counselling at our clinic, and two of these were also unhappy about the post-test counselling they had received. A few respondents felt that the clinic staff had relied too much on written information that was provided to the patients.

Despite these apparent shortcomings in the process of counselling, the majority of informants did not appear to question the circumstances of the HIV test. A few respondents pointed out that HIV testing was the right and responsible thing to do for people who were planning to have a child. Two male informants, however, expressed

overt anger. These men were resentful about having been confronted with the issue of HIV testing at the infertility clinic, and one of them said: "I didn't come here for blood tests [HIV test]... we were trying so long to have a baby... then we decided to come here... now instead of a baby [it] is the HIV story".

In contrast to the quiet acceptance that many informants displayed in the discussion of the test circumstances, respondents described intense emotions when they recalled their reactions to the diagnosis of HIV infection. This included the HIV-negative woman whose husband had tested positive. Informants expressed feelings of shock, devastation, feeling shattered, and feeling overwhelmed by the result. Other reactions included anger and disbelief. Several informants described a range of intense emotions like the following man who had tears in his eyes when he said: "It made me scared, angry, upset... really devastated... I was losing hope, I didn't see anything good in the future... and feeling no joy, no reason to be happy".

Several respondents recalled thoughts of death and dying after receiving their test results. This is expressed in the words of this woman who said "[I thought] my life is finished... because now I'm going to die. I've got nothing, I don't have a baby, it's like my life was all a mistake". Another man explained that although everybody knew they would die one day "it's worse when you know that you are going to die of HIV... because we always think we are going to live a long time... [but] I'm going to die soon... that's very painful". Three informants spoke about suicide. This included one couple in whom both partners had contemplated suicide in response to the HIV test but without sharing these thoughts with each other. Another man spoke in general terms of the risk of suicide in people who were diagnosed with HIV.

Four informants appeared to have coped better when compared to the rest of the study cohort. This included the partner of the woman who was diagnosed with HIV several years ago and who had anticipated the result. Two other participants said that although

their initial reaction was one of shock, they quickly accepted their situation. “I was in shock” one of them explained “when I get home I was worried, ‘why me?’ but after that, because I’m always listening to the radio and TV... [I] just knew I am normal, I am the same person”. Another informant drew support and comfort from her sister, who reminded her that everybody had to die one day and who advised her to think positively. The sister accompanied her to a community support group and promised to learn about the disease in order to share the burden. “After that I felt much better and I didn’t worry much” this woman said.

10.3.5. General Health Status

Twelve informants said that they had not experienced any problems with their health since they were diagnosed with HIV. Of the other five participants one couple had suffered from genital blisters which they had treated with home remedies containing garlic and herbs. Another respondent was told that she had a low CD 4 count (below 300/mm³) when she presented with hair loss and a skin rash but she was neither hospitalised nor started on anti-retroviral medication.

One male informant, who was in general good health, was concerned that the HIV infection was affecting his eyesight. This man had lost his truck driving licence because he failed an eye test. Lastly, one woman had, as already mentioned, been previously diagnosed with tuberculosis. She was the only informant who was on anti-retroviral therapy and who was presenting regularly to the health-sector for follow-up visits. Some of the other informants had gone to their local primary care clinic in order to assess their CD4 status or to obtain more information about HIV/AIDS, but were not under the regular care of any health care facility.

10.3.6. Experiences in the Relationship

Thirteen informants spoke positively about the experiences with their partner following the diagnosis of HIV infection. This included ten informants who were married to each

other and who gave a congruent account of their relationship, and a further two respondents who participated in the study without their partner. Five of these 13 informants were in HIV sero-discordant relationships.

These 13 informants felt that the diagnosis of HIV had either not substantially changed their relationship with their spouse or had brought the partners even closer. Some, however, acknowledged that they had to work through difficult issues. One woman had asked for a divorce after the diagnosis of HIV but her husband, who was HIV-negative, had refused. "I love her more than before, and I don't see anything wrong with her" he said. Another informant emphasised how hard but important it had been to address the "issues" with his HIV-negative wife, and how he valued his wife's support. "It is difficult if the other party doesn't want to understand, then it brings separation and divorce and the [HIV] positive one becomes devastated" he said. Four informants said that being in HIV-positive, sero-concordant relationships made things easier. "We bear the same pain" one woman explained.

One man said that although he intended to stay with his wife and was still hoping for a baby, their relationship was not as close as before both he and his wife had tested HIV-positive. This man was afraid to argue with his wife in case it would result in a fight about HIV, and he spent time away from home at his sister's house.

For three respondents the diagnosis of HIV resulted in the breaking up of the relationship (Table 10.1). One woman had "chased" her HIV-negative partner away after she tested positive because "he was giving me stress" and she did not want his pity. She did, however, indicate that he had remained caring and supportive. Another woman had obtained her HIV result without her partner. With the help of her sister, as outlined above, she had accepted the diagnosis and had advised her boyfriend, whom she described as difficult and often drunk, to check his own results. His reaction was negative and hurtful. She recalled that only the night before he was drunk, calling her name

outside the door and asking “Can I come in, is your AIDS gone?” The woman was able to laugh at the situation and said that she had decided “not to worry” about the relationship.

The narrative of one male informant reflected pain and helplessness when he spoke about the circumstances under which his wife, who was HIV-negative, had left him. After being informed about their HIV status at the clinic, his wife had started an argument outside their home disclosing his HIV status to the neighbours. The man had to move out of the bedroom and “there was no touching or talking about sex”. His wife subsequently broke the news to his parents and then left. When he tried to go after her she became abusive and hurtful. He was particularly hurt when he found that she had left everything behind he had ever bought her. After she left he felt restricted and disrespected as everybody knew that he was HIV-positive “because my wife decided to tell the world”. “I’m just hurting” he concluded “not because of HIV/AIDS, but [because of] the way she treated me and... influenced people to treat me.”

The informants who were still living with their partner (n = 14) were asked how the diagnosis of HIV had affected their sexual relationship. Half of the respondents said they were using condoms regularly. The others did not, or only occasionally, and were hoping to conceive.

All informants who were using condoms found them problematic. One respondent said that although the use of condoms posed no difficulties as such, the knowledge of not being able to conceive was upsetting for his wife. Another man expressed his frustrations at not having been instructed by the staff at the hospital on how to use condoms. He emphasised that healthcare workers should not assume that people knew how to use them. In his opinion this lack of knowledge was the reason why most people were not using condoms. He laughed when he said “Look at me: I’m old enough for anybody to think that I should know, but I didn’t know.” Another woman said that she did not have

enough money to buy “good” condoms at the chemist and that those which were freely available were of poor quality and would often burst.

10.3.7. Living with HIV

Participants had different experiences with adjusting to the diagnosis and continuing their lives in the knowledge that one or both partners were HIV-infected.

Five informants appeared to have adjusted well. Four of these five informants had disclosed their HIV status, at least within their families and had received care and support in return. One HIV-positive woman who was living with her in-laws said: “They all know that I’m HIV-positive, but they don’t have a problem with me. I’m the one who is cooking and doing everything, and nobody will say ‘please don’t do this or that’ or ‘I won’t drink from your cup’ ”. The overall attitude of these informants was reflected in the words of this woman who said: “I must be positive and tell myself that I am going to live and be happy. I am not going to hide... in the corner... feeling shame for myself.”

For the other twelve informants the diagnosis of HIV appeared to have resulted in an ongoing struggle with many challenges and varying abilities to cope with the situation. Feelings of acceptance and confidence appeared to be often intermingled with feelings of pain and sadness in the same informant. Some respondents indicated that they had come to terms with their problem, but then contradicted themselves later in the interview. Two women spoke about how they struggled in situations when others discussed HIV, and one of them was crying when she said “It does affect me socially... when my friends... talk about HIV I feel like shrinking, I don’t want to be involved”. The social difficulties of one of the male informants whose wife had publicly disclosed his HIV status have already been addressed. This man also explained that people who came to visit would avoid touching his belongings and refuse drinks that he offered.

Of the informants who were struggling to come to terms with HIV only two had voluntarily disclosed their HIV status. Both informants had, however, been selective in their disclosure and only told a sibling whom they trusted.

The other participants had not disclosed their HIV status for a number of different reasons and some gave more than one reason. One woman explained that she first wanted to be pregnant in order to soften the news for her family and in-laws. Another one did not want her family to know because the news would cause grief and worry, particularly for her parents. A few informants explained that they first wanted to come to terms with the diagnosis before they told others. Only one couple said that they had not disclosed for fear of being rejected both by the community and by their families.

For the majority of informants the inability to conceive was an important cause of ongoing pain, sadness, and worry irrespective of how well they had adjusted to the diagnosis of HIV otherwise. “What hurts most is not to have a child” one woman said. In addition to the pain of childlessness, some informants struggled with the uncertainties surrounding their wish for a child. “Can I have a baby in my situation?” one woman asked. Another man said “I don’t know what can I do for my wife to have her own child? That is my worry.”

10.3.8. The Wish for a Child

The three respondents who following the diagnosis of HIV were now single had abandoned their hopes and wishes for a child. This caused a lot of pain for one of the women who was crying when she said: “I do not have a choice... so I really pray hard that God gives me the strength to accept... that I cannot have a child”. The other woman felt that her age and her ten-year-old son were reasons not to consider another pregnancy in her situation. The male informant explained that he had wanted to adopt a child, but his wife had responded with anger and abuse to this suggestion. Now that his wife had left

him he wanted to focus on his health and not think about a child. He also indicated that he did not consider it fair to father a child in his situation.

In all other respondents the wish for a child persisted (Table 10.1). Against the background of infertility and refusal of infertility treatment, this wish profoundly shaped the reality of being HIV-positive in the majority of informants. Respondents spoke about hopes and dreams as well as of feelings of anger, pain, devastation, and resentment. Half of these respondents actively tried to conceive while the others did not, but all of them continued to hope that ‘one day’ they would have a child (Table 10.1). Informants contextualised this hope differently.

One couple hoped to conceive through artificial insemination with donor sperm (AID) but had not entered into any infertility treatment at the time of the interview. The woman, who was HIV-negative, emphasised that she would have wanted to have a baby even if she were HIV-positive, because “pregnancy is very important to women”. It was evident that the decision to undergo AID had been difficult for the couple. Both partners expressed anguish at not being able to have their “own” child while at the same time trying to accept the thought of conceiving through AID.

The seven informants who continued in their attempts to conceive spontaneously, hoped just to fall pregnant “one day”. For those who were using contraception the wish for a child was associated with helplessness and with not knowing how to find a solution. Adoption was not perceived as a solution and informants emphasised the importance of pregnancy and of having your own child when married.

A few respondents, both using and not using contraception, directed their hope towards the medical profession either to find a way which would allow them to conceive or to find a cure for HIV. One woman, however, expressed her concerns that finding a cure may take a long time and that she would be too old by then to conceive. Another man

emphasised the importance of accessing medical care in order to conceive and to receive ongoing treatment as he feared that his wife or baby might otherwise die. Finally one respondent placed his trust in God by saying: "I still hope [to have a baby] because I'm still alive and that's why I hope maybe God gonna do something to help [with] HIV."

In expressing their ongoing hope for a child, a few informants emphasised that this hope was either not influenced by their HIV infection or that it was strengthened by the diagnosis. Two of these respondents said that life would be easier and better with a child. Another woman explained that HIV and infertility were both painful conditions which were difficult to bear simultaneously, indicating that if she had a child she would only have to carry one of these burdens. One respondent pointed out that HIV was no different to other medical conditions such as high blood pressure and sugar disease which could also cause problems in pregnancy and result in a reduced life span. "We feel the same... we don't treat ourselves [as] HIV-positive" this person said.

Although motives for parenthood were not systematically explored in this study many respondents forwarded reasons as to why they wanted a child. Informants who were trying to conceive gave similar motives as those who were using contraception. The commonest reason (given by seven participants) reflected the social pressure on a married couple to reproduce. One man reiterated the importance of children when he said: "We Xhosa people... believe that you are not a family when you haven't got a baby". Additional motives for parenthood included strengthening of the marital bond, expectations of happiness, wanting to feel like a parent, to experience pregnancy, to demonstrate fertility, and to have an heir. One woman was crying when she said: "I just want a baby, I don't know why."

Most informants who were still hoping for a child had thought about the future of the child, and all of them had trust and confidence in their (extended) families to help with the raising of the child should this need arise. Respondents who were in sero-discordant

relationships also said that the HIV-negative partner would take care of the child. One woman said that she would deal with possible future problems when they happened. A few informants emphasised that they were hoping that a cure for HIV/AIDS would be found thus solving the possible problem of childcare. Another man pointed out that all parents should prepare for their child's future irrespective of their health.

It is important to emphasise that the wish for a child was often closely interwoven with other themes explored in the interviews. Against the backdrop of infertility the wish for a child shaped informants' responses to the diagnosis of HIV such as the woman who, as previously mentioned, felt that being infertile and HIV-positive was indicative of her life having been a "mistake". The desire for a child also influenced issues relating to health as it prevented use of condoms in several informants. Others hoped to access anti-retroviral therapy in the belief that this would allow access to infertility treatment.

The wish for a child was a central theme in living with HIV. It furthermore played an important role within the marital relationship of several participants. These informants felt that although they had a good relationship with their partner, a child would further strengthen this bond. One woman was concerned that her husband might leave her if the infertility remained unresolved. Another woman said that she knew that pregnancy could be dangerous and even result in maternal death but these risks "did not matter" as long as she could have a baby. "Because I know that my husband will be happy, and my in-laws will look after the baby" she explained. This woman had a child with her husband before they got married. When probed further this woman said: "Sister, you don't understand. We Xhosa people, when you are married you are expected to have a child... that child which was conceived before marriage is not counted."

10.3.9. Perceived Risks of HIV Infection in Pregnancy

After exploring informants' wishes and attitudes towards fertility all participants were asked whether they thought that HIV was associated with possible risks in pregnancy.

All but one respondent knew about the risk of vertical transmission and of the implications of neonatal HIV infection. In addition, several informants indicated that there were drugs which could reduce or eliminate this risk.

Five participants thought that HIV carried no maternal risks or were unsure as to whether they existed. The other twelve participants said that HIV infection was associated with risks for the mother in pregnancy. Four of these participants said HIV could result in maternal death. The others spoke in general terms about women being “sick”, getting “infections”, or being “weak”.

While respondents appeared to have a largely similar understanding of the general risks of HIV in pregnancy, their perceptions of their own vulnerability to these risks differed. Two informants were confident that because of their good health and because of the availability of drugs none of these risks would apply to them. In contrast, two other women believed that pregnancy could result in their own death or that of their child.

In all the other informants the perceptions of their own vulnerability fell between these extreme positions of no perceived risk and possible death. Several participants were unsure about the existence or extent of possible risks like this woman who said: “I don’t know whether I will be sick or not, but I wish to have that baby for my husband”. Concerns and uncertainty are reflected in the words of another woman, who thought that she or her baby could encounter problems in pregnancy and who asked at the end of the interview: “I would like to know... if you are HIV-positive... [and] you fall pregnant by yourself and then you become ill... is there any chance you can be healthy again?” Lastly, two men emphasised that although they were generally aware of possible HIV-related complications in pregnancy, they were not going to worry about these until their partners were actually pregnant.

Careful analysis demonstrated no association between the different perceptions of vulnerability and a couple's decision actively to attempt conception. In other words, those who were trying to conceive appeared to experience the same degree of vulnerability, but were willing to accept these risks, when compared to respondents who were using contraception.

10.3.10. Attitudes to Infertility Management

All respondents were asked what approach, in their opinion, the hospital should take regarding infertility management in HIV-infected individuals.

One male informant who was no longer thinking of having a child felt that the hospital had an obligation to provide anti-retroviral therapy, but not necessarily infertility treatment. Another one said that he did not know the answer to this question.

All other respondents felt that infertility treatment should or must be made accessible to HIV-infected people. Five informants added that it was the hospital's responsibility to deliver this care as illustrated by this man who said: "[It] is the responsibility of the hospital to assist with treatment, they must not tell us that because we are HIV-positive they cannot help us". The HIV-negative woman who was intending to undergo AID stressed the importance of this help when she said: "If I was positive and I wanted to have this baby, they must not stop me... because for me not to have a baby is the saddest thing ever."

A few informants felt that this "help" should be subject to certain conditions. These included that the couple had to carefully consider all the "issues", that prospective parents should be able to afford anti-retroviral therapy for the child, that only married couples should be treated, that infertility treatment should be given for one child only, and that patients should contribute to the cost of treatment.

In verbalising these expectations, some participants spoke about the experience of having been turned away from the infertility clinic because of their HIV status. One informant, as already mentioned, felt pity for her husband. The others recalled feelings of anger, pain, disappointment, and injustice, and the intensity of these sentiments appeared to have largely persisted. "I felt so bad, I am very angry, even at this moment. Why can't we be helped to have a baby and we will see what we can do... I feel that this was unfair, really" one man said. Feelings of pain and injustice were expressed by this woman who was crying when she said: "I think it [is] very unfair...because you do help other people...some people with high blood pressure... why [not] us?" Deep disappointment, hurt, and anger shaped the experience of another woman who felt that her needs and feelings were being ignored.

The three informants who were separated from their partner indicated that they were no longer interested in infertility treatment. All other participants said they would come back to the clinic if, perhaps, one day the medical approach to infertility in HIV-infected people changed. The words of one man reflected the feelings of many others when he quietly said: "I ask you... to protect my wife... and to make us have a baby... I need a baby... if my wife can be protected... and that baby. I ask you to help us."

10.4. DISCUSSION

This is the first study from South Africa which has explored the experiences related to infertility and HIV infection in individuals who were suffering from both conditions and who had, unsuccessfully, tried to access medical help for their inability to conceive. Our results demonstrated that the combination of HIV and infertility was associated with considerable suffering. Importantly, this study documented that the diagnosis of HIV infection did not eliminate the wish for a child and the expectation to be offered infertility treatment among many of our informants.

Many respondents reacted with intense emotions including shock, disbelief, and anger to the diagnosis of HIV infection, and several participants recalled thoughts of death and dying. Although some respondents appeared to be able subsequently to adjust to the diagnosis, HIV infection was an ongoing struggle, despite apparent good health, for many others.

Similar findings were reported in a study by Mill (2003) who interviewed 31 HIV-positive women in Ghana with the aim of ascertaining reactions and adaptations to the diagnosis of HIV infection. Study participants were recruited from HIV outpatient clinics in an urban teaching hospital and two rural hospitals. Although some women quietly accepted their diagnosis, many others recalled feelings of shock, disbelief, anger, and deep concerns when first confronted with their positive test result. Some women contemplated suicide. Following the diagnosis, several women whose status was known to others had encountered negative and humiliating social experiences. Fear of stigmatisation made other informants not disclose their HIV status. The authors called for urgent interventions to reduce stigmatisation of HIV-infected individuals in order to reduce human suffering and, by 'breaking the silence', allow patients better access to health care. Other studies from Nigeria, Ghana and Uganda have similarly borne testimony to the crisis that the diagnosis of HIV can evoke in individuals, to the personal and social difficulties that often follow, and to a high level of stigmatisation (Withell, 2000; Blackstock, 2005; Etuk and Ekanem, 2005).

It is recognised that the HIV/AIDS epidemic is characterised by extraordinarily high levels of stigma which profoundly shape the reality of living with HIV/AIDS for men and women all over the world (Laryea and Gien, 1993; Parker and Aggleton, 2003). Manifestations of HIV/AIDS related stigma range from openly shunning and avoiding physical contact with infected individuals or their belongings to more subtle forms of social discrimination. HIV/AIDS related stigma is evoked by several aspects of the condition which include the infectious nature of the disease, high mortality, lack of cure, immoral behaviour attributed to modes of transmission, and the visible manifestations of

late stage disease. The belief that HIV/AIDS is caused by supernatural forces and/or evil spirits adds to the stigma in many African countries (Mill, 2003; Kalichman and Simbayi 2004). According to Parker and Aggleton (2003) social structures also influence HIV/AIDS related stigma. In highly individualised cultures as found in parts of the USA and Europe, stigma and discrimination is mostly the consequence of individual behaviour. In contrast, the greater sense of family bonds and social allegiances found in many parts of the developing world, causes whole groups of people to participate in stigmatisation and discrimination.

Many HIV-infected individuals in sub-Saharan Africa do not disclose their HIV status because of fear of stigmatisation (Mill, 2003; Nachega et al., 2005; Sethosa and Peltzer, 2005). In addition, studies from South Africa and Zambia have indicated that women fear or experience abuse and violence from their intimate partner in connection with HIV status disclosure (Semrau et al., 2005; Sethosa and Peltzer, 2005). In a review of 29 studies from the United States and sub-Saharan countries which addressed the intersection between HIV and violence the evidence for intimate partner violence secondary to women's disclosure of their HIV status was, however, conflicting (Maman et al., 2000). While some studies indicated that women who disclosed their positive status to their partner were at considerable risk of abuse, other studies reported that men reacted with sympathy and understanding. The authors hypothesized that disclosure may trigger abuse predominantly in men who have a pre-existing history of intimate partner violence.

In this study several informants had not disclosed their HIV status, but only one couple said that this was because of fear of stigmatisation. Others wanted to protect their families from sadness and worry or wanted to come to terms with their condition before disclosing it to others. Importantly, all informants had undergone HIV testing as a couple and had therefore disclosed their HIV status within their intimate relationship. For two respondents this resulted in negative reactions and abuse from their partner, and the person who was worst affected was a man. Although both men and women appeared to

speak openly and sincerely about their relationships, it is possible that some informants did not disclose partner abuse and participants were not probed about this.

Couple counselling and HIV-testing has been recommended in order to reduce the intimate partner abuse secondary to HIV disclosure and to increase the uptake of voluntary counselling and testing, particularly for pregnant women (Baiden et al., 2005). A study from Kenya and Tanzania reported that HIV counsellors perceived couple counselling as being more effective in inducing behavioural changes and reducing relationship disruptions when compared to the counselling of individuals (Grinstead et al., 2000).

There is, however, concern that couple counselling may also increase the risk of abuse, abandonment, and divorce due to partner disclosure inherent in the approach. Semrau et al. (2005) studied the impact of couple counselling on the willingness of pregnant women to participate in interventions to reduce mother-to-child HIV transmission and on their experiences of adverse events within the relationship. The study cohort consisted of approximately 9000 pregnant women who underwent HIV counselling and testing at two antenatal clinics in Lusaka, Zambia. One in ten women underwent couple counselling based on their partner's willingness to participate. Couple counselling neither increased nor decreased negative events within the relationship (abuse, divorce, separation), but increased the number of women who were willing to be tested when compared to women who underwent individual counselling.

Our own observations and the results of these studies indicate that couple counselling is an appropriate approach to HIV testing. The findings in the studies described in chapter 3, 4 and 6 demonstrated, however, that intimate partner abuse may shape the women's experience of infertility. It is therefore possible that women who are HIV-positive and infertile are at dual risk. Further studies are required in order to assess the risk and prevalence of negative events within the intimate relationship in this cohort of patients.

Respondents in this study gave a similar account of their experiences related to their inability to conceive as the informants in the studies described in chapter 3 and chapter 6. Infertility was commonly described as a very painful experience, and several informants emphasised the importance of having children when married. This similarity between the studies was expected as all informants were recruited from the same community and in a similar setting. As these experiences have been addressed and discussed in detail in previous chapters no further discussion follows here.

The observation that the diagnosis of HIV infection did not eliminate the wish for a child in the majority of our respondents was a central finding of this study. Specifically, our results demonstrated that all informants who were able to sustain their relationship following the diagnosis of HIV infection desired fertility. In the absence of help from the health care sector, half of those who wanted a child actively tried to conceive. These findings highlight the central importance that children have in the lives of men and women from our community and underpin the results of the previous studies which have all borne testimony to the value of children.

Our study offers only limited insight as to why, against the common backdrop of wanting a child and a history of infertility, some couples actively tried to conceive while others did not. It is possible that the intensity of the desire for a child is one of the factors which may account for this difference. According to the interviews this desire did, however, not appear to differ between the informants. Parenthood motives, as hypothesised in chapter 9, may be another variable, but we were unable to observe any such association in this study. This lack of association is in keeping with the findings described in chapter 9. The size of this study and the fact that parenthood motives were not systematically explored, however, limits the conclusions drawn in this regard.

The decision to reproduce may also be influenced by an individual's knowledge of risks and his/her perceptions of vulnerability to these risks. All participants appeared

adequately informed about the risks of vertical transmission, but possible maternal risks were less well understood. These findings are in keeping with the results of the study described in chapter 9. Informants in this study expressed different degrees of vulnerability to these risks. Although perceived pregnancy-related risks may have deterred some of the informants from trying to conceive, others were ready to accept these risks, including the one woman who was willing to die if she could give her husband a baby. This lack of association between knowledge and behaviour has been reported from other studies in South Africa and Gabon which have evaluated HIV/AIDS-related knowledge and sexual behaviour among various study cohorts (Friedland et al., 1991; Blecher et al., 1995; Zoguereh et al., 2004; Sethosa and Peltzer, 2005). Further research and larger studies are clearly required in order to determine which factors influence the decision to conceive in the setting of HIV infection. Understanding these factors is important for the appropriate counselling of people who are faced with these problems and decisions.

There is no other study from sub-Saharan Africa with which to compare our findings. In addition, there are few reports from developing countries which have addressed the issues relating to conception among fertile HIV-positive people. In a review of the impact that HIV infection has on the reproductive health of women across Africa, Temmerman et al. (1994) noted that many women with HIV infection choose to become pregnant and that the presence of AIDS defining illnesses or a previous HIV-positive child were not deterring factors in this regard.

In Rwanda, Allen et al. (1993) studied pregnancy and contraceptive use in approximately 1500 women following HIV counselling and testing. One third of the study cohort tested HIV-positive. The post-test counselling of HIV-positive women focussed on the prevention of hetero-sexual transmission, on providing 'moral support', and on discouraging women from childbearing because of the associated risks to mother and child. All women were followed up for two years. The authors recorded low usage of contraception and a two-year incidence of pregnancy of 43% among HIV-positive

women, which was only slightly lower than the number of pregnancies recorded among the HIV-negative participants. Furthermore, many women expressed their wish for more children at the end of the study irrespective of their HIV status. The authors attributed these findings to the fact that women in Rwanda were expected to produce many children in order to ensure family survival. In addition, ongoing childbearing was viewed as a way to continue a 'normal' life-style in the presence of HIV infection.

Panozzo et al. (2003) explored the desire for parenthood in a cohort of 114 HIV-positive, heterosexual men and women living in Switzerland. Data were collected by means of an anonymous, postal questionnaire survey (response rate: 32%). Ninety one respondents were on anti-retroviral therapy. Nearly half of all HIV-positive women and 38% of the HIV-positive men desired children, either currently or in future. The desire for a child was positively associated with a subjective sense of good health but not with the objective parameters pertaining to health status (i.e. CD 4 count or viral load). Many study participants felt that health care providers did not adequately address issues relating to their relationships, sexuality, and fertility.

In Brazil, Paiva et al. (2003) studied the desire for parenthood among 250 sexually active men who had been living with HIV for an average of 5.7 years. Of the participants, 43% indicated that they wanted to have children, a figure which is similar to the study by Panozzo et al. (2003). Two thirds of these men anticipated, however, their doctor's disapproval of parenthood and had therefore frequently fathered children without discussing this issue with their health care providers. This lack of consultation, arguably, contributed to the fact that one third of the participants were unaware of the risk of vertical transmission and only every other informant knew that anti-retroviral medication could reduce this risk. The authors noted that fatherhood was central to masculinity in Brazil and expressed their criticism of health services which were based on 'excellent technological knowledge', but which maintained negative attitudes towards a person's 'constitutional right to form a family'.

Our own study described in chapter 9 documented largely negative attitudes of infertile, HIV-negative couples towards fertility in HIV-infected individuals. It is likely that people who themselves never suffered from the inability to conceive may have an even more negative attitude in this regard. De Bruyn (2004) expressed concern about the negative attitudes of the community and health care workers towards fertility in HIV-infected individuals in South Africa. In her review of the HIV-related challenges in reproductive health care the author emphasised that all women, irrespective of their HIV status, must be allowed to exercise their sexual and reproductive rights which included, among others, the right to have children (de Bruyn, 2004).

In this discussion it is important to consider the negative impact that parental HIV/AIDS may have on the child, particularly in low-resource communities. In addition, studies from Rwanda, Zimbabwe and Uganda have reported that children can also be a burden for HIV-infected people (Keogh et al., 1994; Krabbendam et al., 1998; Withell, 2000). According to these studies HIV-positive women suffered under multiple coexisting pressures, but anxiety and uncertainty related to the current and future welfare of their children were leading concerns which women experienced as particularly traumatic.

In contrast, most informants in our study did not appear excessively concerned about the possible future of a child. In addition, they felt confident that, if required, the extended family would willingly assist with childcare. It is possible that these differences between the other studies and ours relate to a better socio-economic background of our participants when compared to the respondents from Rwanda, Uganda and Zimbabwe. In addition, it must be noted that we recorded perceptions and expectations about children who were as yet unborn compared to real-life concerns and experiences reported in the other three studies.

The results of this study offer new insights into the concerns, hopes and experiences of HIV-infected individuals who, unsuccessfully, sought help from a tertiary infertility

clinic. This must inform our future approach - and that of related clinical settings - to this cohort of patients.

The health sector may, through refusal of infertility treatment, remove from its view one of the many and often insurmountable problems that the HIV pandemic is posing in South Africa and many other sub-Saharan countries. This approach does not eliminate the problem for the patient. The assumption that the diagnosis of HIV infection may stop infertile couples from desiring a child or from expecting medical assistance for conception is, according to this study, mostly incorrect. Instead, health care workers need to be aware that the triad of infertility, HIV infection and refusal of infertility treatment is often an overwhelmingly negative experience which, for some women as well as men, may be further shaped by the experience of abuse from an intimate partner. In addition, there is justified concern that treatment refusal might further spread HIV infection because couples continue to try to conceive, because relationships may break up over the problem of infertility and HIV resulting in new attachments, and because anger and disillusion with the biomedical health sector may limit the uptake of appropriate antenatal care in case of spontaneous conception.

In the first instance this understanding of the patient's perspective needs to inform the process of pre- and post-test counselling. Issues relating to infertility, the relationship, the desired pregnancy, and the approach of the infertility clinic to HIV-infected patients need to be empathetically discussed, together with themes relating to HIV/AIDS. Such counselling may place an additional burden on the limited healthcare resources. Integrating appropriately trained lay counsellors into the process and networking with existing support groups may facilitate adequate counselling and follow-up.

In the second instance, those who are tasked with the delivery of infertility treatment should critically re-evaluate their management approaches to HIV-infected couples against available evidence and available health resources on an ongoing basis. This

evaluation must take cognisance of the suffering associated with infertility and with HIV/AIDS in Africa, and of the related need for intervention. Interventions should, however, not put the health and life of women or their children at risk. They should also be culturally feasible, economically sustainable, and accepted by the community in order to ensure that treatments, or their outcomes, are not discredited (Hamberger and Janson, 1997). In addition, the interest of all related parties must be considered, and this may require the involvement of the extended family in the counselling and decision-making process.

In our own unit this critical analysis has led to a change in the approach to HIV-infected, infertile couples since this study was conducted. Based on the roll-out of programmes aimed at preventing vertical HIV transmission in our community, the advent of anti-retroviral agents for selected patients, and the insight into the patient's perspective gained from this study and the other research underpinning this dissertation, treatment protocols have been developed for HIV-positive, sero-discordant couples. These protocols comprise in-depth counselling, careful assessment of the health, economic status and social support of prospective parents, their ability to access anti-retroviral treatment and, where indicated, access to certain infertility interventions including intra-uterine insemination. This approach takes care of a limited patient population. It does, however, send an important signal with regard to the reproductive health needs of HIV-infected, infertile men and women in South Africa.

10.5. SUMMARY

In this study in-depth interviews were conducted with men and women who were denied infertility treatment at our clinic because of their positive HIV status and/or that of their partner. The experiences related to infertility and HIV infection were associated with considerable suffering. The results documented that the wish for a child and the expectation to receive infertility treatment persisted in all informants who sustained their relationship following the diagnosis of HIV infection. Half of these informants continued to attempt conception without medical assistance, and we were unable to discern which variables influenced this decision. Many participants felt that by refusing infertility treatment the hospital did not fulfil its responsibility to provide public health care.

CHAPTER 11

CONCLUSIONS AND RECOMMENDATIONS

11.1 CONCLUSIONS

The seven studies described in this dissertation have explored how men and women suffering from couple infertility experienced, constructed, and responded to infertility. This chapter presents the conclusions that can be derived from this research. It must be emphasised that these conclusions are applicable to the cohort of patients studied, namely infertile men and women from an urban, low-resource, and culturally heterogeneous community who accessed a tertiary level care infertility clinic in the public health sector in South Africa.

- ❖ Parenthood and fertility were highly valued by our informants. Men and women expressed a strong desire for children and gave many reasons for wanting a child.
- ❖ Not being able to conceive was a distressing experience for most men and women, which induced strong emotional reactions and elevated levels of distress. Infertility frequently elicited negative social consequences including marital instability, abuse, ridicule, loss of social status, and social isolation. While women appeared to carry the main burden associated with infertility, men were also affected. Intimate partner abuse formed part of the experience of involuntary childlessness for some women, and they were particularly distressed.
- ❖ Infertility was constructed through biomedical terms, lay concepts and, at times, traditional beliefs. Men and women had limited biomedical knowledge related to fertility, infertility, and infertility treatment. The use of biomedical terms did not

necessarily imply that patients understood the underlying concept. Lack of knowledge was associated with anxiety, misconceptions about causes of infertility, unrealistic treatment expectations, and difficulties in accessing effective healthcare.

- ❖ Many men were willing and motivated to be involved in the process of infertility management, usually without knowing what this entailed. These men were often supportive of their partner and were aware of the possibility of male factor infertility. Some men, however, refused to participate in the management process, and this created treatment barriers for their partner. Other frequently encountered treatment barriers included lack of effective referral from primary to secondary and tertiary care, inadequate patient information, and long waiting times at clinics and between appointments. Together with patient-related factors, such as missed appointments and prolonged absence from town, these barriers were a cause of treatment non-compliance.
- ❖ The concomitant experience of HIV infection and infertility was associated with considerable suffering. The diagnosis of HIV infection did not eliminate the wish for a child unless it caused separation between partners. Patients appeared accepting of HIV screening at the infertility clinic but perceived their exclusion from further infertility management based on their HIV status as unjust. Several couples, some of whom were sero-discordant, continued to try to conceive. HIV-negative, infertile couples were largely opposed to fertility and infertility management in HIV-positive couples, based on the understanding that HIV/AIDS is a deadly, incurable disease which affects both the parents and the offspring.

11.2. RECOMMENDATIONS

11.2.1. Recommendations for Health Service Delivery

The research presented in this dissertation aimed to describe the patients' perspective of infertility. A central motivation for this research was the desire to improve patient care. Based on the results of our studies, several recommendations for the delivery of infertility-related health care in the public health sector of South Africa can be made.

- ❖ The importance of counselling in the context of infertility management must be emphasised. Counselling, based on an understanding of the reality of infertility in our communities, should form an important part of a patient-centred approach in which psychosocial care is the responsibility of all members of the health care team. This may be particularly important in developing countries where negative social consequences may be more common and more severe when compared to the industrialised world. In addition, professional counsellors can usually not be accessed because of limited resources. As a result the psychosocial support of patients depends on the skills and training of the clinic staff.
- ❖ Our findings highlight that information and health education play an important role in infertility management in South Africa. We recommend that information delivery should be based on an understanding of patients' knowledge and constructs relating to fertility and infertility. Traditional beliefs should be respected and the role of traditional healing needs to be acknowledged within the biomedical health system. Although information delivery must form part of patient management in all countries, it is of particular relevance in the developing world, where men and women may not be able to access other sources of information such as books, the media, or the internet easily and therefore rely on health care workers for information.
- ❖ Infertility-related health care should seek to engage the male partner in all aspects of infertility management. To achieve this, health care workers must have insight into

the male perspective of infertility within their communities and be aware of the reproductive health needs of their male patients.

- ❖ The development of guidelines for the management and the referral of infertile couples within our public health sector is recommended, with due recognition of the complex process that successful implementation of such guidelines entails. At the level of health care planning, the evidence of the negative impact that involuntary childlessness has on the lives of men and women, should be utilised to motivate for the allocation of adequate health resources to facilitate appropriate infertility management.
- ❖ Guidelines are also urgently required for the management of HIV-positive, infertile couples in the public health sector. Although guidelines have to operate within available health resources, they must also be based on an understanding of the reality of HIV infection and infertility and of the implications that exclusion from infertility treatment has for the reproductive health of these couples, and for the possible spread of the epidemic. Moreover, the availability of anti-retroviral therapy in the public health sector is likely both to increase the demand for infertility treatment as well as make such treatment more feasible.

11.2.2. Recommendations for Future Research

In the course of the research presented in this dissertation the need for further studies has become apparent. By addressing some of the following questions, these studies may help to expand our understanding of the problem of infertility in South Africa.

- ❖ *How common is infertility in South Africa?*

The studies presented in this dissertation provide evidence of the negative impact that infertility has on the lives of men and women. In order to assess the magnitude of this impact, epidemiological studies are now required which measure the prevalence of infertility at regional and national level.

❖ *How do men and women living in other areas of South Africa experience and construct infertility?*

Our work has focussed exclusively on men and women living in the Cape Town metropole. Similar studies are required from other urban centres and, importantly, from rural areas, where the lack of infertility-related health facilities may further compound the experience of involuntary childlessness.

❖ *How does education and social status influence both the risk factors for infertility and the associated negative social consequences?*

The answer to this question may allow us to identify men and women who are at particular risk of ostracism and stigmatisation and thereby in extra need of psychosocial support. In addition, it may indicate what role education and a general improvement of the socio-economic status in South Africa may have on fertility-related reproductive health in our communities – particularly for women.

❖ *How does gender shape the experience of infertility and influence health-seeking behaviour?*

The studies presented in this dissertation showed many similarities as well as some differences in the way men and women constructed, experienced, and responded to infertility. Our research was, however, not designed to assess gender differences and further studies are required. These studies also need to assess the extent of male refusal of infertility management and identify underlying reasons for this. Understanding gender in the context of infertility has important implications for the management and counselling of infertile couples.

❖ *Is infertility a risk factor for intimate partner violence?*

The existing literature on domestic abuse has not highlighted infertility as a risk factor, but some of the women in our studies attributed their experience of intimate partner abuse to their inability to conceive. The association between infertility and intimate partner violence requires further research in South Africa.

❖ *How is parenthood constructed in our communities and does this construct differ between fertile and infertile people?*

We piloted the parenthood-motivation list in South Africa. This instrument was developed in the Netherlands. Although statistical analysis indicated that the model could be fitted to our data, further research is recommended in order to assess whether parenthood motives may also be constructed through different items (which are not captured by the parenthood-motivation list) and/or through different interpretation of the same items. Future research in this field should be conducted in collaboration with social scientists. Understanding parenthood motives has important implications for the counselling of infertile couples and may also aid our understanding of reproductive behaviour in South Africa.

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PUBLICATIONS AND PRESENTATIONS

Publications Utilising Data Included in the Dissertation

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- ❖ Dyer SJ, Abrahams N, Hoffman M, van der Spuy ZM (2002).
Infertility in South Africa: Women's reproductive health knowledge and treatment-seeking behaviour for involuntary childlessness.
Human Reproduction, 17(6), 1657-1662.
- ❖ Dyer SJ, Abrahams N, Hoffman M, van der Spuy ZM (2002).
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Human Reproduction, 17 (6), 1663-1668.
- ❖ Dyer SJ, Abrahams N, Mokoena NE, Lombard CJ, van der Spuy ZM (2005).
Psychological distress among women suffering from couple infertility in South Africa: a quantitative assessment.
Human Reproduction, 20(7):1938-1943.
- ❖ Dyer SJ, Abrahams N, Mokoena, NE, van der Spuy ZM (2004).
"You are a man because you have children": Experiences, reproductive health knowledge and treatment-seeking behaviour among men suffering from couple infertility in South Africa.
Human Reproduction, 19(4), 960-967.

International Conference Presentations related to the Dissertation

- ❖ Dyer SJ, Abrahams N, Hoffman M, van der Spuy ZM. Experiences and expectations of patients at initial presentation to Groote Schuur Hospital infertility clinic. Presented at the 4th *International Scientific Meeting of the Royal College of Obstetricians and Gynaecologists*, Cape Town, South Africa, 1999.
- ❖ Dyer SJ, Abrahams N, Carlyle A, Lombard CJ, van der Spuy ZM. Psychological distress in infertile women in a developing country - a quantitative analysis. Presented at the 17th *Annual Meeting of the European Society of Human Reproduction and Embryology*, Lausanne, Switzerland, 2001.
- ❖ Dyer SJ, Abrahams N, Mokoena, NE, van der Spuy ZM. Health seeking behaviour and experiences of men suffering from infertility in a developing urban community. Presented at the 18th *Annual Meeting of the European Society of Human Reproduction and Embryology*, Vienna, Austria, 2002.
- ❖ Dyer SJ, Abrahams N, Mokoena NE, van der Spuy, ZM. Infertility, HIV and parenthood motives in South Africa. Presented at the 20th *Annual Meeting of the European Society of Human Reproduction and Embryology*, Berlin, Germany, 2004.
- ❖ Dyer SJ, Mokoena NE, van der Spuy ZM. "I am still hoping, because I am still alive": experiences and expectations of infertile, HIV-positive men and women in South Africa. Presented at the 22nd *Annual Meeting of the European Society of Human Reproduction and Embryology*, Prague, Czech Republic, 2006.

Local Conference Presentations Related to Dissertation

- ❖ Dyer SJ, Abrahams N, Hoffman M, van der Spuy ZM. Experiences, knowledge and health seeking behaviour of infertile women from a developing urban community. Presented at the 27th *Biennial Meeting of the South African Society of Obstetricians and Gynaecologists* held in conjunction with the *Biannual Meeting of the South African Society of Reproductive Scientists and Surgeons*, Sun City, South Africa, 2001.

APPENDICES

APPENDIX A – Interview Guide (Chapters 3 and 6)

Themes:

- Knowledge of fertility / Understanding of the process of conception
- Knowledge of the causes of infertility
- Health-seeking practices:
 - Which partner accessed help
 - Which resources were accessed
 - Duration of health-seeking
 - Access of traditional health care
- Expectations related to infertility treatment:
 - Nature of treatment
 - Success of treatment
- Social experiences related to the inability to conceive:
 - Personal reactions
 - Experiences within the relationship
 - Experiences within the family
 - Experiences within community

APPENDIX B – Study Questionnaire (Chapter 4) and SCL-90-R (Chapters 4 and 7)

Study Questionnaire

SOCIAL AND DEMOGRAPHIC QUESTIONNAIRE FOR INFERTILITY STUDY	
Interview language: Xhosa = 1 Afrlkaans = 2 English = 3	☐ 1
Interviewer number	☐ 2
Study number	☐ ☐ ☐ 5
Folder number	☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ 13
Date (dd-mm-yyyy)	☐ ☐ - ☐ ☐ - ☐ ☐ ☐ ☐ ☐ ☐ 21
Medical Aid Yes = 1 No = 2	☐ 22

Demographics

1	How old are you?		23
2	What is the highest level of education you have completed? No formal schooling = 0 Grade 1/ Sub A = 1 Grade 2/ Sub B = 2 Grade 3/ Std 1 = 3 Grade 4/ Std 2 = 4 Grade 5/ Std 3 = 5 Grade 6/ Std 4 = 6 Grade 7/ Std 5 = 7 Grade 8/ Std 6 = 8 Grade 9/ Std 7 = 9 Grade 10/ Std 8 = 10 Grade 11/ Std 9 = 11 Grade 12/ Std 10 without matric = 12 Grade 12/ Std 10 with matric = 13 Tertiary (University/ Technikon/ College, degree, diploma or certlificate) = 14		25
3	What is your home language? Afrikaans = 1 isiXhosa = 2 English = 3 Other (specify) = 4 _____		
4	What population group do you consider yourself to belong to? Coloured = 1 Black = 2 White = 3 Indian = 4 Other (specify) = 5 _____		
5	How many rooms are used for sleeping in your dwelling? (<i>Record actual number</i>)		29
6	What is the total number of people living in your dwelling? (<i>Record actual number</i>)		
7	Do you do work for which you are paid? Yes, employed full time = 1 Yes, employed part-time = 2 Yes, employed seasonally = 3 Yes, home/community-based work (healer, craft-maker, seller) = 4 No, home maker = 5 No, looking for employment = 6 No, not looking for employment = 7		
8	If you are working, what type of work do you do? Professional (teacher, nurse, doctor) = 1 Skilled (saleswork) = 2 Un/semi-skilled/ manual (builder, labourer, domestic worker) = 3		
9	Does your partner contribute regularly to the household income? Yes = 1 No = 2		34

Relationship		
16	Are you currently married to your partner? Yes = 1 No = 2	☐ 43
17	How long have you been in this relationship? Less than three years = 1 Three to ten years = 2 More than ten years = 3	☐
18	Will anything change in your relationship if you get pregnant? Yes = 1 No = 2 Maybe = 3 Don't Know = 4	☐
→ If no, go to 20		
19	If yes, please describe what will change? 	☐ ☐
20	Will anything change in your relationship if you do not get pregnant? Yes = 1 No = 2 Maybe = 3 Don't Know = 4	☐ 48
→ If no, go to 22		
21	If yes, please describe what will change? 	☐ ☐
22	Has your partner ever hit you, pushed you, slapped you or threatened you with a weapon? Yes = 1 No = 2	☐
→ If no, go to 25		
23	If yes, would you say this happened once, a few times or many times? Once = 1 A few times = 2 Many times = 3	☐
24	If yes would you say this has been related to you not falling pregnant? Yes, always = 1 Sometimes = 2 No, never = 3	☐
25	Has your partner ever shouted at you, sworn at you, used dirty language or called you rude names? Yes = 1 No = 2	☐ 54
→ If no, go to 28		

Social and Demographic Questionnaire for Infertility Study

Study number: ☐ ☐ ☐

26	If yes, would you say this happened once, a few times or many times? Once = 1 A few times = 2 Many times = 3	☐ 55
27	If yes would you say this has been related to you not falling pregnant? Yes, always = 1 Sometimes = 2 No, never = 3	☐ 56
28	Has anyone else ever shouted at you, sworn at you, used dirty language or called you rude names related to you not falling pregnant? Yes = 1 No = 2	☐ → If no, go to 30
29	If yes, who _____	☐
30	How would you describe your partner's attitude toward you not falling pregnant? Supportive = 1 Unsupportive = 2 Indifferent = 3 Abusive = 4	☐
Support and Communication		
31	Do you have anybody you can talk to about not being able to fall pregnant? Yes = 1 No = 2	☐ → If no, go to 31
32	If yes, who? (<i>Can select more than one option</i>) Partner = 1 Friend = 2 Family member = 3 Healthcare worker = 4 Other (<i>specify</i>) = 5 _____	☐ 61
33	How would you describe your family's attitude towards you not being able to get pregnant? Supportive = 1 Unsupportive = 2 Indifferent = 3 Abusive = 4 They do not know = 5 Unsure = 6	☐
34	How would you describe your partner's family's attitude towards you not being able to get pregnant? Supportive = 1 Unsupportive = 2 Indifferent = 3 Abusive = 4 They do not know = 5 Unsure = 6	☐
35	How would you describe your friends' attitudes towards you not being able to get pregnant? Supportive = 1 Unsupportive = 2 Indifferent = 3 Abusive = 4 They do not know = 5 Unsure = 6	☐

Social and Demographic Questionnaire for Infertility Study

Study number: ☐ ☐ ☐

36 How would you describe your community's attitude towards a woman who cannot fall pregnant?

- Supportive = 1
Unsupportive = 2
Indifferent = 3
Abusive = 4
Don't Know = 5

☐ 65

Help Seeking Behaviours

37 How long have you been trying to get help for this problem? (Record in months)

☐☐☐ 67

38 Who have you gone to for help/ how did you end up here? (Interviewer to probe and list all professional and non-professional people approached for help)

1. _____
2. _____
3. _____
4. _____
5. _____
6. _____
7. _____
8. _____
9. _____
10. _____

☐
☐
☐
☐
☐
☐
☐
☐
☐
☐
☐ 77

Accessibility

39 If you must come to this clinic regularly what kind of transport will you use?

- Walked = 1
Public transport (taxi, bus, train) = 2
Own transport = 3
Other transport = 4

☐ 1

40 How much would it usually cost for you to get here?

R ☐☐☐☐ 5

41 How long (regardless of mode of transport) would it usually take you to get here?

Hrs ☐☐ : ☐☐ 5

42 Would it be easy or difficult for you to get here regularly?

- Easy = 1
Difficult = 2

→ If easy, end interview

☐

43 If difficult, why?

- _____

☐☐ 12

44 How many live children do you have from your current relationship?

☐☐

45 How many live children do you have from **ALL** of your previous relationships?

46 Which day hospital (community health center) is nearest to where you live?

Observations



Leonard R. Derogatis, PhD

Last Name First MI

ID Number

Age Gender Test Date

DIRECTIONS:

1. Print your name, identification number, age, gender, and test date in the area on the left side of this page.
2. Use a No. 2 pencil only and make a dark mark when responding to the items on pages 2 and 3.
3. If you want to change an answer, erase it carefully and then fill in your new choice.
4. Do not make any marks outside the circles.



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INSTRUCTIONS:

Below is a list of problems people sometimes have. Please read each one carefully, and blacken the circle that best describes HOW MUCH THAT PROBLEM HAS DISTRESSED OR BOTHERED YOU DURING THE PAST 7 DAYS INCLUDING TODAY. Blacken the circle for only one

number for each problem and do not skip any items. If you change your mind, erase your first mark carefully. Read the example before beginning, and if you have any questions please ask them now.

	NOT AT ALL	A LITTLE BIT	MODERATELY	QUITE A BIT	EXTREMELY	
1	0	1	2	3	4	HOW MUCH WERE YOU DISTRESSED BY: Bodyaches

	NOT AT ALL	A LITTLE BIT	MODERATELY	QUITE A BIT	EXTREMELY	
1	0	1	2	3	4	Headaches
2	0	1	2	3	4	Nervousness or shakiness inside
3	0	1	2	3	4	Repeated unpleasant thoughts that won't leave your mind
4	0	1	2	3	4	Faintness or dizziness
5	0	1	2	3	4	Loss of sexual interest or pleasure
6	0	1	2	3	4	Feeling critical of others
7	0	1	2	3	4	The idea that someone else can control your thoughts
8	0	1	2	3	4	Feeling others are to blame for most of your troubles
9	0	1	2	3	4	Trouble remembering things
10	0	1	2	3	4	Worried about sloppiness or carelessness
11	0	1	2	3	4	Feeling easily annoyed or irritated
12	0	1	2	3	4	Pains in heart or chest
13	0	1	2	3	4	Feeling afraid in open spaces or on the streets
14	0	1	2	3	4	Feeling low in energy or slowed down
15	0	1	2	3	4	Thoughts of ending your life
16	0	1	2	3	4	Hearing voices that other people do not hear
17	0	1	2	3	4	Trembling
18	0	1	2	3	4	Feeling that most people cannot be trusted
19	0	1	2	3	4	Poor appetite
20	0	1	2	3	4	Crying easily
21	0	1	2	3	4	Feeling shy or uneasy with the opposite sex
22	0	1	2	3	4	Feelings of being trapped or caught
23	0	1	2	3	4	Suddenly scared for no reason
24	0	1	2	3	4	Temper outbursts that you could not control
25	0	1	2	3	4	Feeling afraid to go out of your house alone
26	0	1	2	3	4	Blaming yourself for things
27	0	1	2	3	4	Pains in lower back
28	0	1	2	3	4	Feeling blocked in getting things done
29	0	1	2	3	4	Feeling lonely
30	0	1	2	3	4	Feeling blue
31	0	1	2	3	4	Worrying too much about things
32	0	1	2	3	4	Feeling no interest in things
33	0	1	2	3	4	Feeling fearful
34	0	1	2	3	4	Your feelings being easily hurt
35	0	1	2	3	4	Other people being aware of your private thoughts
36	0	1	2	3	4	Feeling others do not understand you or are unsympathetic
37	0	1	2	3	4	Feeling that people are unfriendly or dislike you

	NOT AT ALL	A LITTLE BIT	MODERATELY	QUITE A BIT	EXTREMELY	HOW MUCH WERE YOU DISTRESSED BY:
38	0	1	2	3	4	Having to do things very slowly to insure correctness
39	0	1	2	3	4	Heart pounding or racing
40	0	1	2	3	4	Nausea or upset stomach
41	0	1	2	3	4	Feeling inferior to others
42	0	1	2	3	4	Soreness of your muscles
43	0	1	2	3	4	Feeling that you are watched or talked about by others
44	0	1	2	3	4	Trouble falling asleep
45	0	1	2	3	4	Having to check and double-check what you do
46	0	1	2	3	4	Difficulty making decisions
47	0	1	2	3	4	Feeling afraid to travel on buses, subways, or trains
48	0	1	2	3	4	Trouble getting your breath
49	0	1	2	3	4	Hot or cold spells
50	0	1	2	3	4	Having to avoid certain things, places, or activities because they frighten you
51	0	1	2	3	4	Your mind going blank
52	0	1	2	3	4	Numbness or tingling in parts of your body
53	0	1	2	3	4	A lump in your throat
54	0	1	2	3	4	Feeling hopeless about the future
55	0	1	2	3	4	Trouble concentrating
56	0	1	2	3	4	Feeling weak in parts of your body
57	0	1	2	3	4	Feeling tense or keyed up
58	0	1	2	3	4	Heavy feelings in your arms or legs
59	0	1	2	3	4	Thoughts of death or dying
60	0	1	2	3	4	Overeating
61	0	1	2	3	4	Feeling uneasy when people are watching or talking about you
62	0	1	2	3	4	Having thoughts that are not your own
63	0	1	2	3	4	Having urges to beat, injure, or harm someone
64	0	1	2	3	4	Awakening in the early morning
65	0	1	2	3	4	Having to repeat the same actions such as touching, counting, or washing
66	0	1	2	3	4	Sleep that is restless or disturbed
67	0	1	2	3	4	Having urges to break or smash things
68	0	1	2	3	4	Having ideas or beliefs that others do not share
69	0	1	2	3	4	Feeling very self-conscious with others
70	0	1	2	3	4	Feeling uneasy in crowds, such as shopping or at a movie
71	0	1	2	3	4	Feeling everything is an effort
72	0	1	2	3	4	Spells of terror or panic
73	0	1	2	3	4	Feeling uncomfortable about eating or drinking in public
74	0	1	2	3	4	Getting into frequent arguments
75	0	1	2	3	4	Feeling nervous when you are left alone
76	0	1	2	3	4	Others not giving you proper credit for your achievements
77	0	1	2	3	4	Feeling lonely even when you are with people
78	0	1	2	3	4	Feeling so restless you couldn't sit still
79	0	1	2	3	4	Feelings of worthlessness
80	0	1	2	3	4	The feeling that something bad is going to happen to you
81	0	1	2	3	4	Shouting or throwing things
82	0	1	2	3	4	Feeling afraid you will faint in public
83	0	1	2	3	4	Feeling that people will take advantage of you if you let them
84	0	1	2	3	4	Having thoughts about sex that bother you a lot
85	0	1	2	3	4	The idea that you should be punished for your sins
86	0	1	2	3	4	Thoughts and images of a frightening nature
87	0	1	2	3	4	The idea that something serious is wrong with your body
88	0	1	2	3	4	Never feeling close to another person
89	0	1	2	3	4	Feelings of guilt
90	0	1	2	3	4	The idea that something is wrong with your mind

APPENDIX C – Interview Guide (Chapter 5)

Themes:

- Clinic-related experiences:
 - General experiences at the first visit
 - General experiences at subsequent visits
 - Treatment satisfaction
 - Treatment barriers
- Understanding of the diagnostic process of infertility management:
 - Quality of information rendered to patients
 - Follow-up arrangements: clarity / waiting periods / difficulties encountered
- Reasons for non-compliance (if applicable)
- Suggestions for improvements of the infertility service

APPENDIX D – Study Questionnaire (Chapters 8 and 9)

Study Questionnaire:

Study NO:

Interviewer:

1. Age of informant
2. Gender : M ☐ F ☐
3. Marital status: Married ☐ Muslim marriage ☐
Traditional Marriage ☐ Common law relationship ☐
4. Number of live children : Total
Current relationship
5. Months of infertility: Total
Current relationship
6. What is the highest level of education you have completed?
7. Do you do work for which you are paid? Yes ☐ No ☐
8. If yes, what type of work do you do?
Professional (teacher, nurse) ☐
Skilled (sales work) ☐
Un/semi-skilled/manual (builder, labourer, domestic worker) ☐

Parenthood-Motivation List

9. Is your wish to have a child as strong as that of your partner?
Stronger ☐ As strong ☐ Not as strong ☐

10. Why do you wish to have a child? A number of reasons are given. Please tell me if you these reasons apply to you. Please choose one of the following three answers to each reason mentioned:

1. I do not agree
2. I agree to some extent
3. I strongly agree with the statement

A. It is nice to have children around	1	2	3
B. It fulfils motherly/fatherly feelings	1	2	3
C. It makes the relationship with your partner complete	1	2	3
D. It is obvious (self-evident) to have children	1	2	3
E. To continue the family name and family tradition	1	2	3
F. Parenthood is satisfying	1	2	3
G. Not to be alone when you are old	1	2	3
H. Children make life complete	1	2	3
I. Your environment (others, family) expect it of you	1	2	3
J. To have a unique relationship with a child (another child)	1	2	3
K. To experience pregnancy and birth	1	2	3
L. Bringing up children brings happiness	1	2	3
M. It gives you a goal to live for	1	2	3
N. It is a sign of being grown-up	1	2	3
O. To have something of yourself continue living after you are dead	1	2	3
P. It is the nature of man and women	1	2	3
Q. Others around me have children	1	2	3
R. To avoid being an outsider	1	2	3

11. Do you keep thinking about the reasons of wanting a child?

Never ☐ Sometimes ☐ Often ☐

12. How strong is your wish to have a child (another child)?

I am willing to give absolutely everything for it ☐

I am willing to give a whole lot for it ☐

I am willing to give a lot for it ☐

I am willing to give something for it ☐

I will accept it if it happens ☐

I do not really care that much ☐

13. How do you currently feel about the fact that you may never have a child (another child) of your own? We want you to list one of seven possible answers:

1. It does not affect me

7. It is the worst thing that ever happened to me.

2-6 Lie in between

HIV / AIDS Questionnaire

14. Did you know that you were HIV negative before this interview? Yes No

15. Have you heard of HIV/AIDS? If so, can you briefly outline what you know about HIV/AIDS?

16. Do you think that a couple in whom one or both partners are HIV positive should have children?

Yes No Depends Don't know

If depends: please specify

17. Now please imagine a couple in whom one partner is HIV positive. The couple would like to have a child but for some reason are unable to do so. Do you think this couple should be given fertility treatment to fall pregnant?

Yes No Depends Don't know

If depends: please specify

18. Now please imagine a couple in whom both partners are HIV positive. Do you think this couple should be given fertility treatment to fall pregnant if they would like to have a child but can't fall pregnant?

Yes No Depends Don't know

18.a If depends: please specify

19. Do you think that pregnancy is more dangerous for women who are HIV positive than for those who are not?

Yes No Depends Don't know

19.a. If depends, please specify:

19.b. If yes / depends: What do you think are the dangers/risks for a pregnant woman who is HIV positive?

20. Do you think the HIV infection in the mother is dangerous for the baby?

Yes No Depends Don't Know

20.a. If depends, please specify:

20.b. If yes / depends: What do you think are the risks/dangers for the baby?

21. You and your partner were tested and you do not have HIV. If the tests had shown that either one or both of you were HIV positive, would you still continue coming to this clinic and trying to get help to fall pregnant?

Yes No Depends Don't know

If depends, please specify:

22. Any other comments

APPENDIX E – Interview Guide (Chapter 10)

Themes:

- Social experiences related to the inability to conceive
- The HIV test:
 - Circumstances of testing
 - Pre- and post-test counselling
 - Reactions to HIV test result
- General health status
- Experiences of living with HIV infection:
 - Personal experiences
 - Experiences within the marital relationship
 - Impact on sexual relationship incl. contraceptive use/barrier methods
 - Experiences within family/community
 - Impact on the wish for a child
- Knowledge of HIV-related risks in pregnancy
- Expectations and attitudes related to future reproductive health care

Latent Trait Modelling of the 18 Items and 6 Parenthood Motives

Although it is possible to perform latent trait analysis with 3-category data (in this instance the three possible answers to each item) the analysis is considerably simpler and more readily performed within existing statistical programs with 2-category data. For this reason the 3-category responses were coded into binary responses in which 1 ('I do not agree') was left unchanged and 2 ('I agree to some extent') and 3 ('I strongly agree') were both coded as 0. It must again be emphasised that the latent trait analysis was used to test whether the model of the parenthood motivation list could be appropriately applied in our setting. For the actual analysis of the raw data factor analysis was conducted as in the original study by van Balen and Trimbos-Kemper (1995).

In the analysis of the 18 individual items a gender difference was observed (Table F.1 and Table F.2). The results of male and female participants were therefore analysed separately. A latent trait analysis was performed of each of the six triplets using package 'ltm' in program R (Rizopoulos, 2005). In each of the resultant 12 sub-analyses (six triplets with both male and female data) a model with one latent trait was fitted and the observed pattern of responses compared with the fitted, or expected, pattern. The observed pattern refers to the eight possible triplets, (000), (100), (010), (001), (110), (011), (101) and (111) resulting from (0,1) responses to three items.

Table F.1. Responses of women to the 18 items of the parenthood-motivation list

Responses 1 = I do not agree

Responses 2 = I agree to some extent

Responses 3 = I strongly agree

Item	Responses		
	N = 50		
	1	2	3
Happiness			
Nice to have children	0	1	49
Unique to relationship *	0	3	47
Children bring happiness	1	6	43
Well-being			
Completes relationship	3	13	34
Makes life complete	7	9	34
Goal to live for	2	16	32
Identity			
Obvious	3	19	28
Sign of grown-up	22	13	15
Nature	3	13	34
Parenthood			
Parental feelings	0	5	45
Parenthood is satisfying	1	7	42
To experience pregnancy	7	10	33
Social control			
Environment expects it	7	14	29
Others have children *	16	16	18
Avoid being outsider *	18	11	21
Continuity			
Continue name / tradition	4	9	37
Not to be alone when old *	5	23	22
To continue living	2	27	21

* Items more strongly enforced by women when compared to men ($p < 0.05$)

Table F.2. Responses of men to the 18 items of the parenthood-motivation list

Responses 1 = I do not agree

Responses 2 = I agree to some extent

Responses 3 = I strongly agree

Item	Responses		
	N = 50		
	1	2	3
Happiness			
Nice to have children	1	3	46
Unique to relationship *	2	9	39
Children bring happiness	2	8	40
Well-being			
Completes relationship	3	22	25
Makes life complete	10	12	28
Goal to live for	3	16	31
Identity			
Obvious	1	28	21
Sign of grown-up	25	14	11
Nature	2	18	30
Parenthood			
Parental feelings	1	11	38
Parenthood is satisfying	0	9	41
To experience pregnancy	10	15	25
Social control			
Environment expects it	11	17	22
Others have children *	29	13	8
Avoid being outsider *	27	11	12
Continuity			
Continue name / tradition	5	14	31
Not to be alone when old *	10	26	14
To continue living	6	27	17

The single latent trait model has 6 parameters so that a chi-square goodness of fit statistic applied to the observed and expected frequencies of the response pattern has the expected value of 1. Any result smaller than 1, or slightly exceeding 1, indicates a good fit. The 95th percentile of the chi-square distribution with one degree of freedom is 3.96.

As an illustration Table F.3 presents the details of one of the 12 sub-analyses. The results of the chi-square calculations for all 12 sub-analyses are summarised in Table F.4.

Table F.3. Details of the latent trait analysis of the triplet coding for well-being

Pattern	Observed Frequency	Expected Frequency	Formula *
000	9	10.50	0.214
001	8	6.06	0.621
010	6	4.07	0.915
011	2	4.13	1.098
100	2	1.29	0.391
101	3	4.14	0.314
110	2	3.14	0.414
111	18	16.68	0.104

* Formula = (observed frequency – expected frequency)² / expected frequency

Table F.4. Chi-square statistics of the observed and expected differences in the response pattern to the six triplets according to latent trait modelling

Triplet	Motive	Women		Men	
* Item no.		D.F. **	χ ²	D.F.	χ ²
1, 10, 12	Happiness	0	0.00	1	0.62
3, 8, 13	Well-being	1	0.11	1	4.07
4, 14, 16	Identity	1	3.12	1	0.08
2, 6, 11	Parenthood	1	0.03	1	3.35
9, 17, 18	Social control	1	2.68	1	0.98
5, 7, 15	Continuity	1	1.26	1	0.74

* Item number = order in which item is asked in the parenthood-motivation list (see Table 8.1).

** D.F. = degree of freedom

The largest chi-square value was observed in the triplet coding for well-being among men indicating the weakest fit of the model in this category. In contrast, perfect fit of the model was observed in the category happiness for women, as fewer than six possible combinations were observed which made the calculation of the chi-square test redundant. Importantly, the mean of the observed chi-square values was 1.55. Based upon this finding the overall fit of the model was deemed satisfactory.

Factor Analysis of the Parenthood-Motivation List

The results of the factor analysis are presented in Table F.5 (women) and Table F.6 (men).

Table F.5. Factor loadings and communalities with varimax rotation (female respondents)

Item	F1	F2	F3	F4	F5	F6	Communality
1	0.720	-0.101	0.167	-0.022	0.120	-0.136	0.590
2	-0.020	0.121	0.143	-0.973	0.108	0.077	1.000
3	0.167	-0.469	0.132	0.053	-0.035	-0.031	0.270
4	0.325	-0.011	0.860	0.253	-0.267	-0.074	0.985
5	-0.089	-0.565	0.172	-0.065	-0.274	0.004	0.436
6	-0.034	-0.209	-0.004	0.450	-0.196	0.558	0.597
7	0.303	-0.068	0.654	0.156	-0.199	0.314	0.686
8	0.065	-0.120	0.640	-0.125	-0.112	0.081	0.463
9	0.428	-0.389	0.103	-0.084	-0.171	0.406	0.547
10	-0.059	-0.107	0.199	0.151	-0.134	0.241	0.154
11	-0.174	-0.180	0.164	0.078	-0.500	0.157	0.370
12	-0.189	-0.512	0.220	0.176	-0.286	0.216	0.505
13	-0.285	-0.455	0.616	0.177	-0.160	0.103	0.735
14	0.013	-0.258	0.655	0.096	-0.089	0.209	0.556
15	-0.176	0.016	0.557	-0.055	-0.118	0.801	1.000
16	0.204	-0.652	-0.008	-0.155	-0.059	0.209	0.538
17	0.313	-0.316	0.166	0.024	-0.747	0.188	0.819
18	-0.092	-0.076	0.210	0.126	-0.934	0.052	0.949
Triplet	(1,10,12)	(3,8,13)	(4,14,16)	(2,6,11)	(9,17,18)	(5,7,15)	

Table F.6. Factor loadings and communalities with varimax rotation (male respondents)

Item	F1	F2	F3	F4	F5	F6	Communality
1	-0.027	0.005	-0.073	-0.168	-0.027	0.414	0.206
2	-0.078	0.125	0.029	-0.913	0.001	0.379	1.000
3	0.777	-0.360	-0.052	0.105	-0.015	-0.058	0.750
4	0.461	-0.239	-0.372	0.251	0.213	0.432	0.672
5	-0.083	0.027	-0.081	-0.013	0.090	0.727	0.550
6	-0.133	-0.050	-0.204	-0.420	0.228	0.035	0.292
7	0.461	-0.379	-0.217	-0.046	0.053	0.609	0.778
8	0.620	-0.036	-0.084	0.061	0.049	-0.165	0.426
9	0.062	-0.142	0.172	-0.195	0.164	0.371	0.256
10	-0.060	-0.100	-0.301	0.040	0.235	0.061	0.164
11	0.164	-0.477	-0.151	0.023	0.246	-0.036	0.340
12	0.020	-0.319	-0.069	0.047	0.046	0.203	0.152
13	0.231	-0.947	-0.197	-0.057	0.049	-0.073	1.000
14	0.310	-0.241	-0.857	-0.332	0.027	0.005	1.000
15	0.160	-0.297	-0.541	0.005	0.078	0.332	0.522
16	-0.134	0.014	-0.064	-0.065	0.145	0.253	0.111
17	0.033	-0.205	-0.024	-0.198	0.907	0.114	0.918
18	0.356	-0.066	-0.319	-0.005	0.557	0.275	0.618
Triplet	(1,10,12)	(3,8,13)	(4,14,16)	(2,6,11)	(9,17,18)	(5,7,15)	

Reference:

Rizopoulos D. (2005) *R Package for fitting latent trait models under the item response theory approach*. Available: <http://med.kuleuven.be/biostat/software/software.htm> [access September 2006]