

**Out of pocket payment for assisted  
reproductive techniques:  
How do households recover?**

By

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## Abbreviation List

ART	Assisted reproductive techniques
DALY'S	Disability-adjusted life years
DHS	Demographic and health surveys
HIV	Human immune-deficiency virus
HH	House-holds
IVF	In vitro fertilisation
NGO	Non-governmental organisation
OPP	Out of pocket payment
SACBIA	South African consortium for benefit incidence analysis
STATSA	The national statistical authority
STI	Sexually transmitted Infection
UN	United Nations
WHO	World Health Organisation

## **Declaration**

I, Latiefa Vinoos, hereby declare that the work contained in this dissertation is my original work and work by others has been acknowledged as such and that neither the whole work or part of it has been, is being, or is to be submitted for another degree in this or any other university.

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## **Abstract**

**Title:** Out of pocket payment for assisted reproductive techniques (ART): How do households recover?

**Introduction:** The cost of ART remains amongst the most prevalent barriers to treatment, especially in resource limited countries where many people are poor and inadequately covered by private and public health insurances. This study aims to assess the financial consequences of out of pocket payment for ART in the South African setting and the ability of couples to financially recover.

**Methods:** A prospective follow-up study was carried out at the Infertility Clinic of the Reproductive Medicine Unit, Groote Schuur Hospital and Faculty of Health Sciences, University of Cape Town. All 135 participants from the original study were invited to participate with no exclusion criteria. A six part questionnaire, developed for the original study, was adjusted to assess recovery from out of pocket expenditure for ART. Indicators of recovery included the recuperation of savings, settlement of debt and reacquisition of sold assets. Persistence of coping strategies such as reduction in spending and additional work was also assessed.

**Results:** A follow-up rate of 54% percent was achieved. The minimum and maximum follow up period was three and five years respectively. Nineteen percent of couples reported complete financial recovery, assessed as the recovery of savings, repayment of all debt and recovery of a sold asset. Forty percent of couples were unable to settle their debt incurred during the original study. The average amount still owed was R 7 750 (SD R5 140). At follow up, 75% of couples who had reduced expenditure to offset the original cost of ART were still reporting a reduction in expenditure while 39% were still engaged in additional work. The majority of couples reporting difficulties at the time of follow up in paying bills or for basic amenities and healthcare were from the poorest socioeconomic tertiles with 64% of all couples indicating that they were not coping financially at the time of follow up.

**Conclusion:** This study documented a long-lasting impact of OPP for ART among all HH but especially among the poorest. Given the high prevalence of infertility, its impact on individuals, couples and communities, the associated mental, emotional and financial consequences, and existing barriers to adequate and affordable treatment should be minimised as South Africa is moving towards the implementation of a national health system.

## **1. Introduction and Literature review**

Parenthood is one of the most universally desired adult goals (Boivin et al, 2007; Dyer, 2007, Holton et al., 2011, Lampic et al., 2006, Langdridge et al., 2005, Peterson et al., 2012, Roberts et al., 2011). In many societies, childbearing is highly regarded to the extent that it may be seen as a cultural norm. Despite a global downward trend in fertility rates (Becker and Nachtigall, 1994; Fidler and Bernstein, 1999), an overview of global parenting surveys, indicated that around 95% of people expressed the desire to have children at some point in their lives (Lampic et al, 2006).

Reproduction is seen as an innate drive within the human psyche and is responsible for the primal evolutionary success of life. In saying this, fertility in many cultures is seen as the essence of womanhood. It often describes, or even more so defines the role of a woman in many societies.

## 1.1 Infertility and Culture

Fertility is defined as the natural ability to produce live offspring. The meaning and motivation for parenthood varies considerably among cultures (van Balen and Bos 2010). Individuals in developed countries place more emphasis on the fulfilment of personal happiness and enhancement of interpersonal relationships through the enjoyable experience of having a child (van Balen and Trimbos-Kemper, 1995; Langdrige et al., 2005). In contrast, strong pronatalist attitudes reflected in many developing countries, mean that children are highly desired and parenthood is “culturally mandatory” (Inhorn 2009). Emphasis is placed on the role of children in the community. In studies from Asia and Africa, families are held in high esteem by their communities as a result of child bearing and the subsequent contributions of these children to their society (Dyer and Patel, 2012). It follows thus that infertility, especially in low-resource settings, is commonly and frequently associated with negative psychosocial and potentially dire consequences for the individual, the couple within their home and in the societal context.

Although these multidimensional effects of infertility are felt by both men and women, there are fewer studies focusing on the psychosocial effects of male infertility. The psychological effects of male infertility, although less well described especially in low resource settings, may often be associated with negative connotations towards sexuality and masculinity (Inhorn, 2002; (Chachamovich et al., 2010).

The majority of studies of infertility in low resource settings have been expressed through the woman’s experience. A large body of existing literature revealed a complex interface between the psychological self-impact of infertility as well as that of external pressures on childless women.

The recurring themes of the effects of infertility were echoed in studies across the world. From Nigeria and Ghana, studies revealed the psychological aspect of infertility where the deeply seated notion that a woman’s self-respect and womanhood were dependent on motherhood (Hollos et al., 2009). In China, one third of all infertile women seeking

treatment had impaired psychological well-being. Their treatment deteriorated with the failure of fertility enhancing treatment (Lok et al., 2002). In South Africa, thirty in-depth interviews of women seeking medical assistance for involuntary infertility revealed the personal suffering caused by their inability to conceive, the subsequent marital instability, stigmatization and abuse as a result of their childlessness (Dyer et al., 2002). Some women were subject to domestic violence, neglect, divorce, social isolation and ostracism (van Balen and Gerrits, 2001; Dyer et al, 2007; van Balen and Bos, 2009; Gerrits and Shaw, 2010).

Personal suffering and disruption to family and social life caused by infertility was further mirrored across the globe in other communities such as Egypt (Inhorn 1991), Nigeria (Okonofua, 2000), Mozambique (Gerrits, 1997) and Bangladesh (Nahar *et al.*, 2000). Moreover, in the middle-East and sub-Saharan Africa, infertile women often faced social isolation and scorn. They may even be turned away from life rituals that involve femininity, fertility and children (Inhorn, 1994, 1996, 2009). Studies in Bangladesh revealed that childlessness placed women at risk of social and familial displacement (Papreen et al., 2000). These inequalities are compounded when infertile women were expected to care for the children of others (Okonofua et al., 1997; Dhont et al., 2011) or to function as a social servant by tending to the sick and aged (Okonofua et al., 1997; Ruganga et al., 2001).

According to a Demographic Health Survey conducted in 2004, barren women in Latin America were more likely to be divorced or separated when compared to women with children. This dissolution of the union was reflected across continents in a study in Rwanda where women were also subjected to abuse (Dhont et al., 2011). Other studies further described marital discourse including a higher incidence of polygamous relationships. Wives were at times even expected to pay back their dowry or to pay for that of a new partner (Nahar, 2012; Nahar et al., 2011). Infertile women were reported to have a higher incidence of being infected with Human Immuno Deficiency Virus (HIV) (Rutstein et al, 2004). Some authors have reported increased exposure to domestic violence and emotional and verbal abuse from the extended family (Nachtigall, 2006). Women were noted to suffer financially by being forced to forfeit their

inheritance and be denied accommodation in their deceased husbands' estates (Hollos, 2003; Hollos et al., 2009).

According to anthropological research, lack of child bearing may be detrimental to financial security for families especially in the context of financial welfare in old age (Inhorn et al, 2003) where children form a consistent source of manpower (Feldman-Savelsberg, 1994; Gerrits, 1997; Hollos, 2003; Barden O' Fallen, 2005; Hollos et al., 2009). Religious implications were not spared, with a study in Botswana revealing the belief that God and their forefathers were punishing the infertile women. (Mogobe, 2005).

Family planning programmes are encouraged in low-resource settings to decrease the number of unwanted or unplanned pregnancies. Despite the possible option of adoption as the management of infertility, childless women or couples are often reluctant to pursue this path due to cultural or religious beliefs (Bharadwaj, 2003; Inhorn, 2006). Further barriers noted for child adoption in Nigeria were stigmatization, financial implications and technical/ regulatory problems with adoption process (Oladokun 2010).

## 1.2 Infertility in a global perspective

According to the World Health Organisation (WHO), the definition of health is not solely the absence of disease or infirmity, but is a holistic state of physical, mental and social well-being. Infertility per se is not a direct cause of death yet it has a significant effect on the overall well-being of the sufferer including far-reaching psychosocial implications.

Infertility is noted to be a global reproductive health problem affecting approximately nine to fifteen percent of reproductive-aged couples in both the developed and developing world (Vayena et al, 2002; Boivin et al., 2007, Fathalla 1992). The presumption that infertility is not a problem in densely populated areas where the fertility rates are high, is inaccurate (Ombelet, 2009). Despite political emphasis placed on family planning awareness and population control in developing countries (Hamberger and Janson, 1997; Daar and Merali, 2002), child bearing remains highly desired (Becker and Nachtigall, 1994; Fidler and Bernstein, 1999).

According to data from 47 Demographic and Health Surveys (DHS) in low-resource countries, 26 being in Africa, an estimated 186 million ever-married women of reproductive age (15-49 years) were infertile in 2002. The proportion was as much as a twenty-five percent of ever- married women (Rutstein et al, 2004).

Infertility gained recognition as a reproductive health and a human rights issue at the International Conference on Population and Development held in Cairo (1994). Access to comprehensive infertility treatment was recognised as a reproductive right for infertile men and women. The *'right of men and women to be informed and to have access to safe, effective, affordable and acceptable methods of family planning of their choice, as well as other methods of their choice for regulation of fertility which are not against the law, and the right of access to appropriate health-care services that will enable women to go safely through pregnancy and childbirth and provide couples with the best chance of having a healthy infant'* was endorsed at the International Conference on Women held in Beijing in 1995. Subsequently, the World Health Organisation (WHO) described accessibility to the delivery of infertility treatment and assisted reproduction as a key

millennium challenge (Vayena et al., 2001) and eventually universal access to reproductive health became Millennium Development Goal 5b (United Nations 2002).

Infertility has thus gained increasingly significant awareness over the last few decades and the importance of patients' access to care as well as the need for quality care has been recognised.

### **1.3 African perspectives and causes of infertility**

While infertility is a global phenomenon, sub-Saharan Africa was observed to have the highest rates of secondary infertility ranging from 12.7 to 30.2% compared to the rest of the world (Rutstein and Shah, 2004; Leke et al., 1993). The reason for this high infertility rate in central and southern Africa is commonly attributed to high rates of sexually transmitted infection (STI) causing both tubal factor and male factor infertility. When compared globally, infection rates are two to four times higher in this region (Vayena et al, 2002; Nachtigall, 2006). The most common offending organisms in STI's include chlamydia, gonorrhoea and/or tuberculosis (Serour and Hefnawi, 1982; Serour et al., 1982; WHO, 1987). In Durban, South Africa, a tubal factor was identifiable in as many as 77% of the infertile population (Chigumadzi et al., 1998). Non-STI causes of tubal factor infertility are also common and include postpartum sepsis and iatrogenic sepsis. Other contributors towards infertility are urbanization, polygamy, drug resistance and delayed/ absent diagnosis or inappropriate treatment of genito-urinary tract infections (Giwa-Osagie, 2002).

Male factor infertility contributed to half of all cases of sub fertility globally and was noted to be caused by previous infections of the male genitourinary tract (Irvine, 1998; Kuku and Osegbe, 1989). Despite the significant male factor contribution to infertility, it is rarely acknowledged and women were often held responsible for couples' inability to conceive (Dhont et al., 2010, Inhorn, 2003).

Based on the above causes, emphasis on primary prevention of STI's, unwanted pregnancies and health education has been emphasised as the most cost effective approach to the treatment of infertility in low resource settings (Leke et al., 1993, Vayena et al., 2002b). This strategy, however, inadvertently overlooks the emotional, relational and economic effects on couples who are already the subjects of involuntary childlessness (Inhorn 2009). There is a large movement towards assimilating the combination of preventative strategies (van Balen and Gerrits, 2001, van Zandvoort et al., 2001) and that of infertility related care including ART (Geelhoed et al., 2002, Makuch et al., 2010, Ombelet et al., 2008, Sundby et al., 1998, Vayena et al.,

2002b). This combined strategy is not a novel idea as it was already supported by the Economic Covenant adopted by the United Nations General Assembly in the 1970's. It recognized the entitlements and rights of everyone to enjoy the benefits of scientific progress and its applications, and the right of everyone to enjoy the highest standard of both physical and mental health.

## **1.4 Opposition to assisted reproductive techniques (ART) in low resource settings**

### 1.4.1 Population burden

A common counter argument to ART in low resource settings is based on the theory of economic modernisation, whereby the cause of economic stagnation and underperformance is thought to be directly related to over population. While economically plausible, this theory overlooks the biopsychosocial impact infertility has on the infertile couple. Initially an individual problem, it may escalate to a societal problem not only impacting the interpersonal relationships of the sufferers but also that of health care facilities through relentless health seeking behaviour. This viewpoint amongst some health administrations has been likened to an unethical population control policy violating the definition of reproductive health that is “the ability to reproduce if, when and as often as they wish,” (United Nations’ International Conference on Population and Development 1994.) An analogy coined would be withholding life prolonging medication for chronically ill patients in order to control population numbers.

### 1.4.2 Adoption

Adoption has been motivated as a cost effective solution to infertility as the numbers of orphans in developing countries are high. This approach, as discussed previously, does not take into consideration cultural views and practises of the specific population wherein adoption could be considered unfavourable. Furthermore, it denies the importance of reproductive autonomy while further distributing social responsibility for overpopulation unjustly upon the infertile (Mahmoud F).

## **1.5 Assisted reproductive technology in low resource settings**

Globalisation of ART has allowed 85% of the world's population to live in countries with access to ART (Collins 2002). Despite the increasing availability and the established need for it, the introduction of ART in low resource settings remains controversial and poses a gauntlet of challenges to health administrations. These include the allocation of already limited resources to ART services, the eligibility criteria for treatment and the importance of reaching the most cost effective balance between investments in preventative versus curative strategies.

### **1.5.1 ART and Health administrations in low resource settings**

Under resourced health systems that barely cope with offering the most basic of health services often do not identify fertility treatment as a priority. This was concluded in a study by Nahar, where in-depth interviews with government and non-government organizations, policy makers, donors and public health researchers were held in Bangladesh. The burden of infertility, lack of accessibility to treatment and the inadequate clinical expertise and facilities were noted (Nahar, 2012).

The general consensus in these health systems is that scarce resources should be distributed to benefit the majority of the population. Preventative strategies target all women of reproductive age and are therefore considered by the many developing health administrations to be more cost effective than the treatment/ cure of the considerably smaller group of infertile couples.

Further delineating these two strategies, preventative versus ART strategies are often perceived as mutually exclusive and all forms of ART are often deemed unfeasible. Some authors argue that governmental policies limiting the distribution of state resources was used in the past to deny women's rights, such as the right to education and further likened this seemingly abusive misappropriation of funds to include infertility treatment. (Sen)

Those in support of ART have placed emphasis on a more holistic approach to infertility. These include the development of cost considerate ART solutions and the creation of more innovative practises with translational benefits across all economic settings.

### 1.5.2 Preventative versus Curative Management

The movement towards subsidized ART versus the population restriction and family planning movement seems paradoxical. However, both are closely linked. The global encouragement of families to accept the norm of smaller families through voluntary contraception and delayed childbearing makes the need for access to ART more significant.

Unlike other forms of infertility treatment, assisted reproductive technology (ART) has been shown to be the most effective and cost-effective treatment (Ombelet, 2009, Vayena et al, 2009) for those suffering from tubal pathology which has been noted to be particularly prevalent in Southern Africa. In the case of severe male factor infertility, ART has also proven to be more beneficial than more conservative interventions (Inhorn, 2009).

### 1.5.3 Underestimation of the scope of the problem in low resource settings

The biggest reflection of inequity is that the majority of childless couples in developed countries compared to developing countries have easier access to medical care, including assisted reproductive technology (ART), with presentation rates to health care facilities as high as seventy-five percent in the former group (Boivin et al, 2007). Often the cost of ART is subsidized by government and health insurance schemes (Chambers et al, 2009).

In contrast, in resource limited countries, the cost of treatment has been noted to be amongst the most prevalent barriers to treatment where many people are poor and inadequately covered by private and public health insurances (Nachtigall, 2006; Inhorn, 2009).

Further compounding the disparity, a Gambian study revealed that only 40% of women in 800 households (HH) who were diagnosed with subfertility, sought care in the formal medical health system. Despite their presentation to the health-workers, limited fertility related investigations and treatments were offered (Sundby et al 1998). Similar sentiments of lack of access and of quality care were expressed across Sudan, West Africa and Vietnam (Hörbst, 2012, Khalifa and Ahmed, 2012, Pashigian, 2012).

The low percentage of presentation rates in poorer HH could be attributed to the lack of confidence couples felt towards the health system. Further compounding the lack of presentation, South African studies revealed that higher income HH were twice more likely to report illnesses than those in the lowest-income HH (McIntyre and Gilson, 2005) and spent a higher proportion of their available income on seeking health care than poorer groups (Makinen et al). McIntyre et al (2007) also showed that a quarter of the lowest socio-economic tertile did not seek medical care at all. The true burden of infertility in low resource settings therefore, may be dramatically underestimated due to possible underreporting in resource restricted communities. The fertility issues faced by current health systems may well be underrepresented.

#### 1.5.4 Consequences of inadequate services

It follows that the combination of the lack of presentation for care in poorer income homes, the dearth of standardised and adequate fertility care and the highly emotional state of the sufferer poses a difficult combination in the low resource setting. As a result, infertile women out of desperation often engage in relentless health-seeking behaviour (van Zandvoort et al., 2001).

Many of these couples seek the alternative assistance including that of traditional healers. While limited evidence is available for the efficacy of such treatments, patients may be subject to exploitation in some instances. One example from literature from Nigeria and the life histories from Senegal revealed that traditional healers may financially or sexually abuse infertile women, but according to one Nigerian informant

this 'was the price to pay' in order to conceive (Okonofua et al.,1997; Seybold, 2002) (Dyer Patel 2013).

#### 1.5.6 Health Tourism

Some countries experienced an influx of the more affluent couples seeking alternative, effective and affordable infertility care of whom many are from resource restricted settings. This cross border care has been witnessed in South Africa in both the private and public health systems. Although this approach may allow couples to gain access to care, concerns arise regarding the true cost-benefit ratio and whether couples have adequate insight of the nature and success of fertility treatment and the compounding costs (Ombelet 2014). Furthermore, this leads to the depletion of the developing countries foreign currency revenues. Ombelet and Van Balen therefore placed emphasis on the upskilling of local healthcare providers by experts from high income countries in the fields of reproductive medicine, nursing, counselling, embryology and administration (Ombelet and Van Balen, 2012). Not only would this approach improve local expertise, it may reduce the phenomenon of health tourism.

#### 1.5.7 Other Economic Considerations

Further economic considerations in developing countries should include the economic role that children play in support of aging parents. A single child could potentially contribute to supporting both parents that may be reliant on the already strained social welfare budget. Due to the multidimensional effects on the individual and community, infertility treatment should receive even more recognition than that received in developed countries.

## 1.6 Affordable ART practices in low resource settings

Despite this evident need for ART centres, there is lack of evidence and ongoing debate surrounding the affordability of ART in low resource settings. The World Bank attempted to prioritise the disease burden according to a quantitative assessment of the disability-adjusted life years (DALY's) in low resource settings in order to effectively distribute the national resources. This led to the noticeable absence of infertility as a health priority as per definition, it was neither a disease nor a disability. In order to avoid oversights of this nature, an argument was proposed that patient experiences and perceptions of the health condition should also be considered when profiling the disease burden in the form of qualitative assessments (quality adjusted life years) (World Health Organisation 2002).

'The physical and psychological burden the infertile couples are willing to go through, and the financial cost couples are willing to pay if they can afford it, attest to the high ranking of infertility as a perceived burden of disease' (Women's Health Council 2009). While qualitative data exists describing this psychological impact and patient perceptions of infertility, few studies have explored the economic impact of ART-related costs on patients and no studies have explored the recovery from OPP for ART related costs. In 2001 WHO announced that infertility should receive recognition as a global health problem. This resulted in a focus shift towards not only access to health care but for more affordable approaches to ART without compromising the quality and outcome of the care.

The integration of simple forms of infertility investigation and treatment (ovulation induction and artificial insemination) with the existing reproductive health setting was suggested as a possible option (Ombelet, 2009). Another preference for low resource settings was the introduction of simplified protocols with significant reduction in cost per cycle for ART. Ombelet further surmised that the simplifying of laboratory equipment, reduction in superfluous investigations and less costly ovarian stimulation were strategies to reduce the cost of ART (Ombelet et al., 2008).

While favourable results were noted in mild ovarian stimulation such as similar live birth rates, reduced patient drop out, reduced ovarian hyper-stimulation syndrome, fewer embryos for cryopreservation and reduced cost per cycle (Fauser et al., 2010), it has not been recommended as the standard of care due to many underlying concerns (Revellie *et al.*, 2011; Siristatidis *et al.*, 2012). The concerns for overall cost effectiveness include the lack of data in developing countries and reports of lower pregnancy rates in women of lower socio-economic status and in non-Caucasian women when compared to those undergoing conventional stimulation ART. A further concern was finding equilibrium between lower ART costs with lower pregnancy rates and increasing cycles with increasing cost. In the developing world this is especially important as couples often have to pay in full or at least in part, for their own treatments (Shahine *et al.*, 2009; Verberg *et al.*, 2009; Bosch and Ezcurra, 2011; Revellie *et al.*, 2011; Smith *et al.*, 2011).

Other strategies suggested to reduce costs and improve accessibility to treatment in Sudan (Khalifa and Ahmed 2012) and West Africa (Horbst 2012) were the decentralisation of infertility care and increased private-public partnerships. These partnerships may prove invaluable as they have the potential to attract foreign investment, create a standard practises, regulations, audits and procurement of the necessary skills training/expertise.

The local production of infertility drugs would drastically reduce the cost of ART while the profits accrued by the partnership could be ploughed back into the health budget to alleviate other areas of concern. An example of this is in India, where affordable health care is offered to those from wealthier countries as they have a competitive edge due to refined low cost strategies, involvement of non-governmental organisations (NGO's) and the lower cost of living and labour. Furthermore, medication could be bought in larger quantities reducing the unit price and improving affordability for both private and public patients.

Like all novel treatment, the initial cost of the treatment will gradually decline once ART becomes easily accessible due to increased competition.

It remains a major challenge in developing countries to implement government funded cost-effective, easily accessible (to the majority of the population) and simplified assisted reproduction programmes with favourable live birth rates. Reassuringly there is a growing body of research exhibiting the effectiveness of low- cost ART and the potential adoption of these methods in low resource settings.

## 1.7 Financial Coping Strategies

The financial implications of ill health have gained increasing attention as one of the main contributors to poverty in low resource settings. Financial coping strategies are adoptive actions undertaken by the HH to alleviate economic strain allowing the HH to maintain its livelihood. The types of coping strategies adopted by HH to counter healthcare costs, give us an important insight into the immediate well-being of the family as well as their future welfare.

The concept of coping strategies was initially described in response to famines in Africa in the mid 1980's by Amartya Sen. Attention was drawn to the potential danger for a HH in sacrificing an investment or lucrative asset (Sen 1981).

A study in Burkina Faso, explored HHs' strategies to cope with illness (Sauerborn et al 1996). These strategies included: utilising cash and mobilising savings, deferring expenditure (i.e. education), sale of assets, loans, income diversification, gifts, mutual support and reduction on food. In a further study, Longhurst and Moser (1998), explored coping strategies within three categories namely; production, social and expenditure. The production category included diversification of income, domestic mutual support, minimisation of current commitments to others and sale or mortgage of assets, while the social category included the breaking of social ties and interaction. The expenditure category comprised a combination of decreasing on total spending, change in dietary habits, followed by reduction in purchase of non-essential items. An amalgamation of coping strategies is adopted in HH affected by ill health depending on the type and extent of the costs incurred.

Generally the reduction in non-essential items were the primary coping strategy followed by accessing disposable income, borrowing of money, the sale of assets (including income generating assets) and lastly a reduction in essential items such as food. The degree to which essential items or consumption was reduced in order to pay for out of pocket expenses was dependant on the severity of the illness (Gertler, Levine & Moretti, 2002). Subsequently research has documented that there are similar responses to the costs of ill health across different countries and types of illness.

However, the types of coping strategies HHs adopt were dependent on the HH's economic, social and cultural features (EQUINET Study, 2000).

For example, in an Ethiopian study of health shocks, weekly HH food expenditure was decreased by a quarter if the head of the HH became ill (Asfaw & Von Braun, 2004). In some studies, education was seen to suffer in order to facilitate for OPP (Russel 2006). In keeping with education, children from HH affected by HIV mortality and a resultant reduction in HH income were taken out of school to work (Pitayanon, Kongsin & Janjareon, 1997). In contrast to the above strategies, other countries protected HH consumption and financed out of pocket payment (OPP) through transient reductions in consumption or through other means. In China, HH temporarily reduced expenditure on food and education that was not demonstrated in follow-up studies (Wilkes, Hao, Bloom & Xingyuan, 1997). In rural Bangladesh, relocation to an alternative dwelling was noted in a small percentage of HH while education expenditure was not reduced (Desmet, 2000).

A number of studies also suggest that multiple presentations of infertile patients to health care institutions lead to compounding costs of treatment (Bergstrom 1992; Buss and Inhorn 1993; Okonofua 1996; Sundby et al 1998; Stewart-Smythe and Van Iddekinge, 2003). Many infertile couples access care despite the cost of treatment (Habbema, 2008). Furthermore, a multitude of factors may motivate some couples to seek ART, even to the extent of enduring impoverishing and catastrophic expenditure (van Balen and Gerrits, 2001; Dyer, 2007; van Balen and Bos, 2009; Gerrits and Shaw, 2010).

## 1.8 Economic Considerations related to ART

Financial risk protection against illness includes two combined mechanisms: risk pooling and prepayment. The latter may involve government funded systems, social health insurances, community based health insurances (voluntary membership and controlled by community) and private health insurances based on monthly premiums (Gottrieb and Schieber, 2006).

In the partial or complete absence of financial risk protection, health care costs are covered through out-of-pocket payments (OPP) by health care seekers (Dyer et al, 2012). This absence of financial protection against health-related costs is a short-coming of many health systems especially in lower- middle and low income countries.

Out-of-pocket payments are considered the most ineffective and inequitable means of financing health care (Knaul et al, 2008) and often encompasses a significant portion of the HH disposable income. The non-subsidisation of ART with resultant OPP in these countries is often rationalized in terms of population control, scarcity of health care resources and infrastructure, and the heavy burden of other life-threatening disease (Inhorn 2009).

Quantitatively, catastrophic expenditure is commonly defined as 40% of annual HH expenditure, after subtracting the cost of food, although some researchers use 20% as an acceptable threshold (Xu et al, 2003, 2007, Habbema, 2008). In qualitative terms, catastrophic expenditure is defined as health costs that threaten the survival of individuals or their HH because of financial collapse, or cause or deepen poverty (Dyer and Patel, 2012; O'Donnell *et al.*, 2008). Several publications have documented the high rates of catastrophic and impoverishing health costs incurred through OPP, and the results thereof have received international recognition (Knaul et al, 2008).

After conducting a systematic review of the literature relating to out-of-pocket cost of infertility treatment in developing countries, Dyer and Patel concluded that infertility treatment could lead to financial ruin in those who invested their already limited resources in seeking treatment. The systematic review included studies from Northern

India where it was found that half of couples had spent in excess of a quarter of the national average annual income per capita and concluded that the expense was a 'considerable expenditure' (Singh et al., 1996). In Rwanda 50% of women spent double their monthly income on fertility treatment that included ovulation induction and antibiotic treatment. A collection of life stories from Nigeria revealed that some wives/women had to pay for fertility treatment with their own earnings or forfeit care (Hollos 2003). Treatment in Gambia's public sector was perceived to be of limited quality while good doctors were unaffordable (Sundby, 1997). While the above literature, to some extent describes OPP in quantitative terms, there is a dearth of information regarding the financial recovery of patients incurring OPP.

Globally the cost of ART was documented in an international survey of 25 countries. This survey reported that the mean cost of a single IVF cycle ranged from \$1300 in Iran to \$6400 in Hong Kong. In all these countries the cost of a single IVF cycle was more than half the average individual's annual income (Collins, 2002). Similarly in Canada, the cost of ART was 25% of the average annual household expenditure in Canada and 50% of an individual's annual disposable income in the USA. The authors concluded that 'if unsubsidized, direct cost for ART represents a significant burden to patients' (Collins, 2002; Connolly et al., 2010).

In the South African context, the majority of ART centres are established in the private health sector. Most medical aid schemes do not offer funding for ART. The Reproductive Medicine Unit at Groote Schuur Hospital is one of two hospitals in South Africa providing comprehensive tertiary level infertility care within the public sector. At this institution, ART is partly subsidised by government and partly reliant on self-funding through OPP. The self-funding component needs to be paid upfront prior to the commencement of treatment, and the average OPP is in the range of R8000 to R12000 per treatment cycle. If initial cycles are unsuccessful, couples may undergo further treatment cycles but this requires further OPP.

Previously, there were limited studies documenting OPP for specific health services or conditions (Daivadanam *et al.*, 2012; Onwujekwe *et al.*, 2012; Smith-Spangler *et al.*,

2012) with none of them relating to infertility. Subsequent to the obvious lack of information regarding OPP and infertility, the Reproductive Medicine Unit at Groote Schuur Hospital conducted a study.

## 1.9 Previous Research at our Institution

Researchers in the field of Reproductive Medicine and Health Economics at Groote Schuur Hospital and Faculty of Health Sciences, University of Cape Town have previously documented the occurrence of catastrophic expenditure due to OPP for ART (Dyer et al, 2013). In order to describe this previous study, some background information is required. The Reproductive Medicine Unit at Groote Schuur Hospital is one of very few health services in South Africa which offers tertiary level infertility care within the public sector. This care includes ovulation induction, artificial insemination, ART, surgery and counselling. Annually, over 500 couples are newly referred from the geographical service area of the hospital. . ART is primarily offered to couples with tubal pathology, severe male factor, age-related infertility or when other non- ART methods have failed.

One hundred and thirty five couples undergoing ART participated in a study exploring OPP of ART. A questionnaire was developed for the purpose of the study which included standard questions used previously in national HH surveys conducted by STATSA (the national statistical authority) and the SACBIA (South African Consortium for Benefit Incidence Analysis).(see Appendix A- Original Questionnaire). Additional questions captured direct and indirect costs for ART, financial coping strategies and the impact of OPP on the HH. Couples were recruited consecutively during the study period but only participated once, meaning that couples undergoing a repeat ART cycle in the study period were excluded from re-entering the study. According to results, one in five couples incurred catastrophic expenditure for ART defined as OPP that was equal to or exceeding 40% of the annual non-food HH expenditure. When this threshold was lowered to 20%, over two-thirds of couples incurred catastrophic expenditure. Significant predictors for catastrophic expenditure were unemployment, no medical aid cover and a lower level of education (primary or secondary level). Lastly, stratification of HHs into socio-economic tertiles demonstrated that 66% of HHs in the poorest tertile experienced catastrophic health care expenditure compared to 7% of HHs in the richest tertile.

The most frequently used financial coping strategies were accessing savings, borrowing money, selling assets and reducing household expenditure on luxury as well as non-luxury (food, rent, schooling) items. Food, entertainment and clothing were the main commodities on which households reduced spending. Essential utilities such as rent, water and electricity were also seen to be reduced. Fifty percent of couples took on extra work in order to survive financially. Lastly, children's education and paying for existing children were also areas where some couples decreased payments in order to mobilise funds (Dyer et al, 2013). Regarding further impact of the OPP, 40% of HHs struggled to pay their bills, 37% could not afford HH basics and 32 % could not pay for health care needs other than IVF. Impact was also measured by means of a five point Likert-scale according to which, over half the HHs was coping but with difficulty, while nearly 5 % felt that the survival of the HH was threatened.

The aim of this follow-up study was to assess the financial recovery of these 135 couples and HHs.

## 2 **Aims and Objectives:**

### 2.4 **Aim:**

To explore the extent of financial recovery of 135 HHs who participated in a previous study exploring OPP expenditure for ART at Groote Schuur Hospital.

### 2.5 **Objectives:**

To determine quantitatively in all participants:

2.5.1 The number of HH reporting full recovery from previous ART expenditure

2.5.2 The number of HHs who have not fully recovered as indicated by:

- Savings utilised and not regained
- Debts/loans outstanding
- Assets previously sold and not recovered

2.5.3 The number of HHs who continue to reduce spending and/or take on additional work

### 3 **Patients and Methods:**

#### 3.4 **Research Design**

A prospective follow-up study.

#### 3.5 **Setting:**

This follow up study was carried out at the Infertility Clinic of the Reproductive Medicine Unit, Groote Schuur Hospital and Faculty of Health Sciences, University of Cape Town.

#### 3.6 **Recruitment and sample size**

All 135 participants from the original study were invited to participate. An information sheet was emailed, faxed or telephonically conveyed outlining the description and aim of the study. Patients who were willing to participate were asked to come to the IVF Clinic or were recruited telephonically. There were no exclusion criteria.

#### 3.7 **Study Instrument**

The six part questionnaire, developed for the original study, was adjusted for the purpose of this follow-up (Appendix B- Adjusted Questionnaire). In particular answers to the following questions were captured:

- 3.7.1 Had the HH regained any savings accessed for ART?
- 3.7.2 Had the HH paid off all debt, if debt had been incurred due to ART?
- 3.7.3 Had the HH re-acquired all assets that had been sold to finance ART?
- 3.7.4 Was the HH struggling to pay bills, for basic amenities or health? (measured on a 4 point Likert scale from never, not very often, fairly often, very often)
- 3.7.5 How did the HH cope currently with the financial impact of the OPP (measured on a 5 point Likert scale from minimal impact, manages easily, copes with difficulty, still recovering and survival threatened)
- 3.7.6 Was the HH still utilising the financial coping strategies of additional work and/or reduced spending?)

### **3.8 Data Collection and processing:**

The revised questionnaire was administered by the primary researcher, Latiefa Vinoos, who was not involved with the infertility service. Xhosa and Afrikaans versions of the questionnaire were available. Prior to interviewing a participant, the interviewer reviewed the answers to the original questionnaire. The completed original questionnaire was thus on hand at the time of this follow up interview.

Recruitment occurred over a one year period. Completed questionnaires were entered into the original study data base by the researcher. This original data base was adjusted to accommodate the follow up data.

## **4 Data Analysis**

Demographic data, coping strategies and recovery from cost were evaluated by descriptive analysis. Dependent variables were identified, namely recovery from cost and coping strategies. These were cross analysed with data from the original study to establish relationships and associations. Pearson Chi squared test was used to determine statistical significance, with significance determined as  $P < 0.05$ .

Likert scales were scored and analysed. For further analysis data was dichotomised and compared to the original study using Chi squared test.

Data were analysed for the entire study group and for the following sub-groups:

- HH ranked in the lowest, intermediate and highest socio-demographic tertile according to the original study. Note: HH were kept in their original socio-economic tertiles to assess financial recovery of couples based on their original tertiles.
- HH who did versus who did not incur subsequent expenditure.
- Participants who had not fallen pregnant were categorised into those with resolved versus unresolved fertility desire. The resolved group comprised couples who had accepted their infertility. The unresolved group comprised

couples intending to pursue infertility treatment. The two groups were compared to identify whether financial reasons were the cause for couples no longer pursuing ART.

## 5 Results

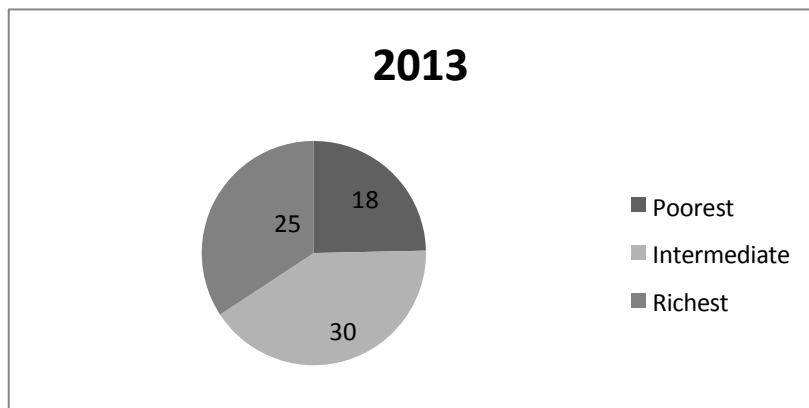
Of the 135 original couples, 48 were lost to follow-up and 14 declined interviews. Seventy three patients participated in the follow-up study.

Ten interviews were conducted at the Infertility Clinic at Groote Schuur Hospital in a quiet private room. The remaining 63 participants were unable or unwilling to attend the Infertility Clinic and their interviews were conducted telephonically. All participants opted to be interviewed in English. Due to the majority of patients requesting telephonic dialogue, only female partners were interviewed. The availability of the female partners contact details made it easier to interview the female partner. It was also easier to interview one person telephonically as opposed to having a group discussion that is more complex to interpret and capture.

### 5.4 Demographic Information

The follow-up study was conducted with a minimum and maximum of three and five years after the initial study interview. The mean and median age of female participants was 42 years with a range of 31 to 52 years as represented in Figure 1. The majority of patients were of mixed ethnicity, locally referred to as Coloured (n=42;58%). Black African and White patients were equally represented (n=14;19%). The remaining three couples (4%) were of Indian descent. Seventy two couples were still in the same relationship. One couple had separated.

**Figure 1. Socioeconomic distribution of HH 2010 vs 2013**

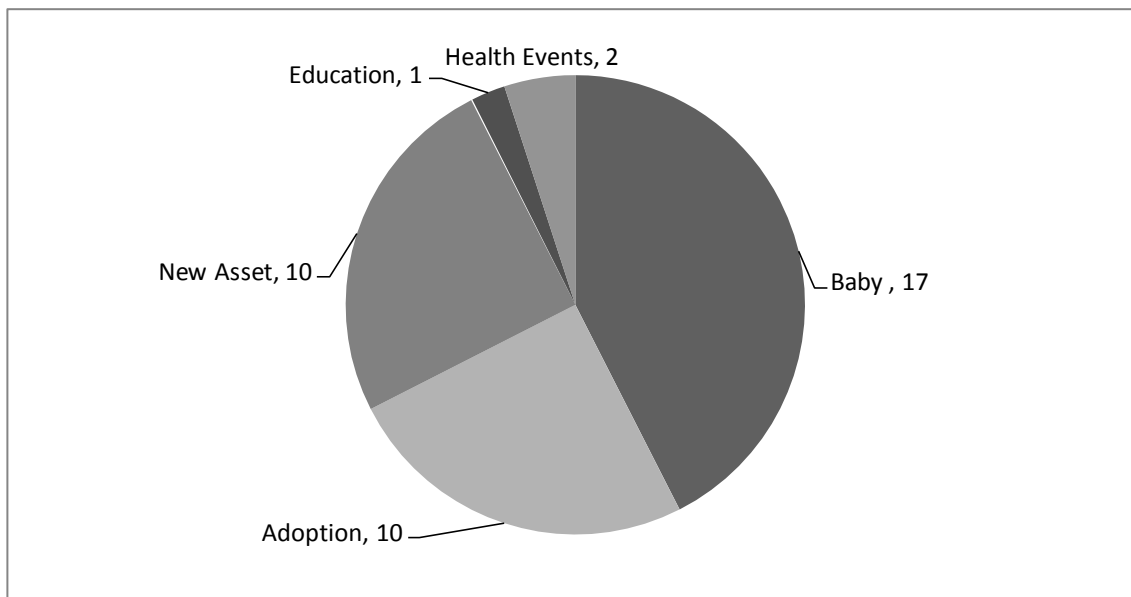


The follow-up rates in the poorest, intermediate and richest groups respectively were 25%, 41% and 34%. Although the majority of couples who participated in the follow-up study were in the intermediate socio-economic tertile, there was no significant difference in the follow up rate between tertiles implying that all tertiles were adequately represented. .

Participants reported an average monthly HH expenditure of R15 850 (Range: R3 000-R50 000). Eight had changed their place of dwelling. Of these, three couples had moved into smaller accommodation for financial reasons while five couples purchased a new home or moved into bigger premises.

Forty patients (54.7%) experienced new major financial demands since the original study. The pie chart in Figure 2 shows the nature of these demands.

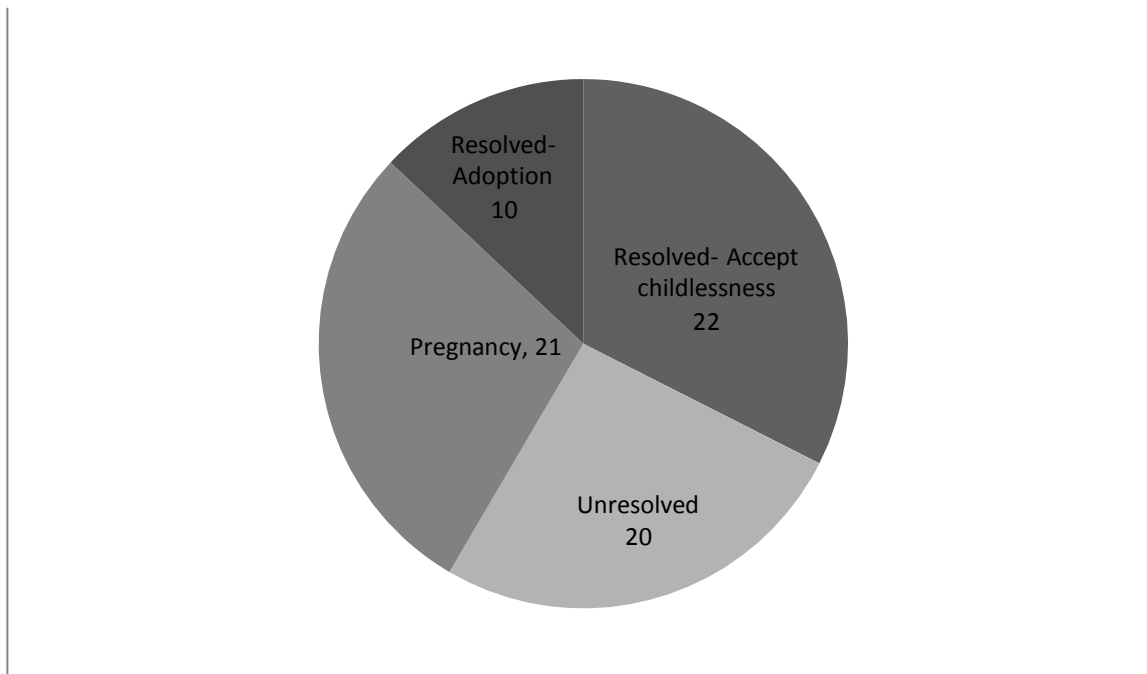
**Figure 2. HH experiencing new financial demands**



### 5.5 Fertility-related information

Of the 73 couples participating, 21 (28.8%) had conceived: 17 (23.2%) due to ART at the time of the original study, two couples following a subsequent ART cycle, and two couples reported a spontaneous conception. These 21 pregnancies resulted in 17 live births and 4 pregnancy losses. Of those without pregnancy, 20 (27%) were currently undergoing or planning IVF in the future (unresolved fertility desire group). The remaining 32 couples (resolved fertility desire group) had decided either to accept childlessness (n=22) or to adopt (n=10; Figure 3).

**Figure 3. Fertility outcome**



### **5.3. Economic data and coping strategies**

#### **5.3.1 Debt, savings and assets**

Thirty five out of 73 couples had borrowed money to fund the original treatment (48%). Of these 35 couples, 14 (40%) had not settled their debt at the time of follow-up. The average amount still owed was R 7 750 (SD R5 140). Nineteen of the 35 couples experienced a new financial demand, which included a baby in nine couples, since the original OPP for ART, however there was no significant association between new expenditure and ongoing debt ( $p=0.79$ ).

Almost all couples, ( $n=68$ ; 94%) had accessed their savings to fund ART. One third of couples (34%), reported that they recovered almost all ( $n=8$ ) or all ( $n=15$ ) of their savings, while the remainder of couples ( $n=45$ ; 66%) reported that they had recovered very little ( $n=26$ ) or none ( $n=19$ ) of their savings.

Thirteen couples (17.8%) had originally sold assets to fund ART; of these 10 (77%) had been unable to recover the asset. Again, no association was found between asset recovery and new financial demands or positive pregnancy outcome. ( $P= 0.63$ )

#### **5.3.2 Financial recovery of debts, savings and assets at time of follow-up**

Seventy one of the 73 participating couples had utilised one or more of the financial coping strategies of accessing savings, selling assets or borrowing money at the time of the original OPP. Complete financial recovery, assessed as the recovery of savings, repayment of all debt and recovery of a sold asset, was reported by 14 couples (19.7%). A breakdown of recovery according to type and number of concomitant coping strategies is shown in Table 1.

The recovery rate in couples originally adopting a single coping strategy was 41.9% while there was no recovery in couples adopting a dual approach, and only one in six couples using three coping strategies managed to recover.

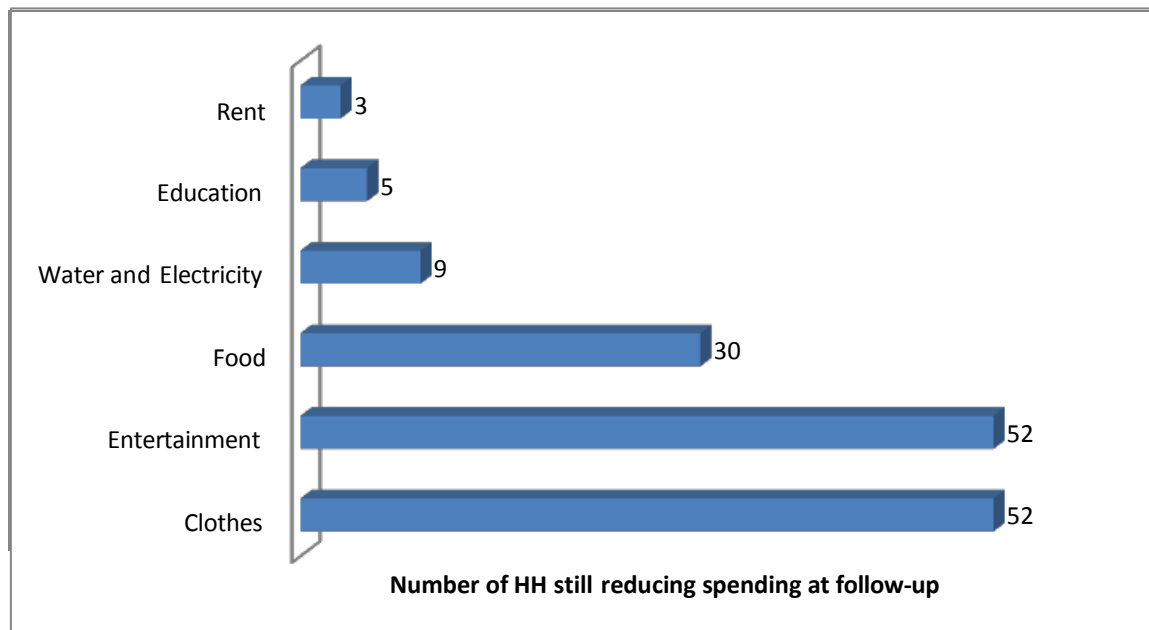
Table 1. Financial recovery of HH

<b>Adopted coping strategy</b>	<b>Total of HH adopting this strategy in the study (N</b>	<b>Complete recovery (Regained savings and/or asset and/or repaid Debt)</b>	<b>Recovery Rate In the group (%)</b>
<b>Single Coping Strategy</b>			
<i>Accessed Savings</i>	29	12	41%
<i>Borrowed money</i>	2	1	50%
<i>Sold asset</i>	0	0	0%
<b>Total</b>	31	13	41.9%
<b>Dual Coping Strategy</b>			
<i>Savings and debt</i>	27	0	0%
<i>Savings and Assets</i>	6	0	0%
<i>Debt and Assets</i>	1	0	0%
<b>Total</b>	34	0	0%
<b>Three coping strategies</b>			
<i>Savings, Debt and Assets</i>	6	1	17%
<b>Grand total</b>	71	14	19.7%

### 5.3.3 Reduced spending and extra work

The additional coping strategies of reduction in HH expenditure and taking on of extra work was utilised by 68 (94%) and 39 couples (54%) at the time of the original OPP. At follow up, 52 couples were still reporting reduced expenditure while 20 were still engaged in additional work resulting in a recovery rate of 23.5% for reduced expenditure and 61.5% for additional work. . Figure 4 depicts the nature of ongoing reduced expenditure.

**Figure 4. HH reduction in expenditure**



### **5.3.4 Ability to pay bills, for basic amenities and health care**

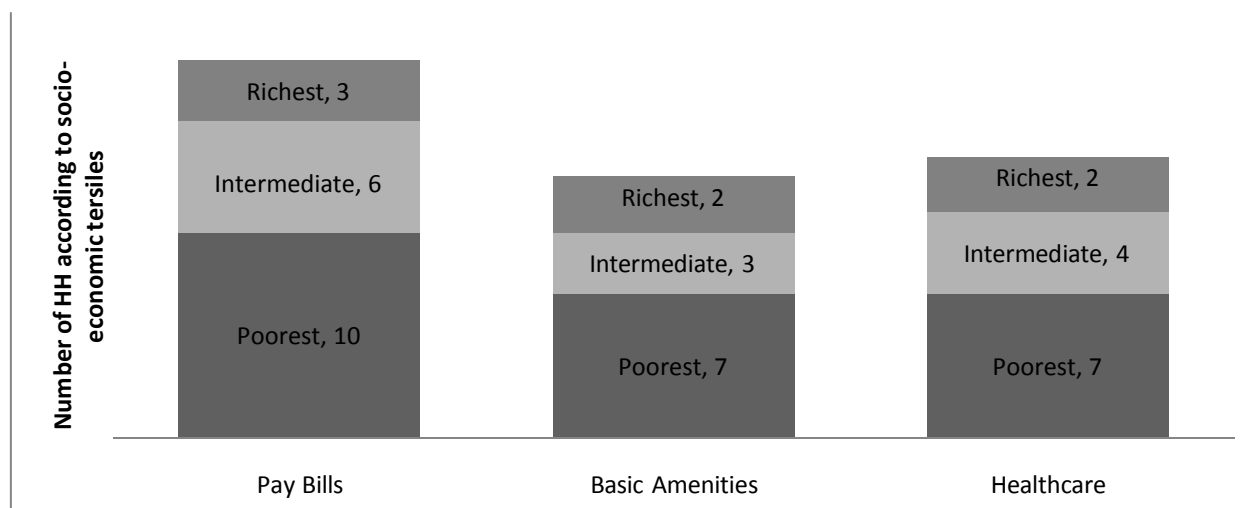
Table 2 summarises data from the original study and at follow up pertaining to HH struggling to pay bills or for basic amenities/health care.

**Table 2. Non recovery in HH vs new struggles**

	<b>2010 (N)</b>	<b>Struggle resolved in 2013</b>	<b>2013 (N)</b>	<b>Continued struggle (N)</b>	<b>New struggle (N)</b>
<b>HH struggled to pay bills</b>	21	12	19	9	10
<b>HH struggled to pay for basic amenities</b>	16	9	12	7	5
<b>HH struggled to pay for health care</b>	17	9	13	8	5

Figure 5 reflects these financial difficulties according to the original socioeconomic tertile. The majority of couples reporting difficulties at the time of follow up in paying bills or for basic amenities and healthcare were from the poorest socioeconomic tertiles (52.63%, 58.33% and 53.85% respectively).

**Figure 5. HH struggling to pay bills, for basic amenities and for healthcare**



### **5.3.5 Financial impact of OOP**

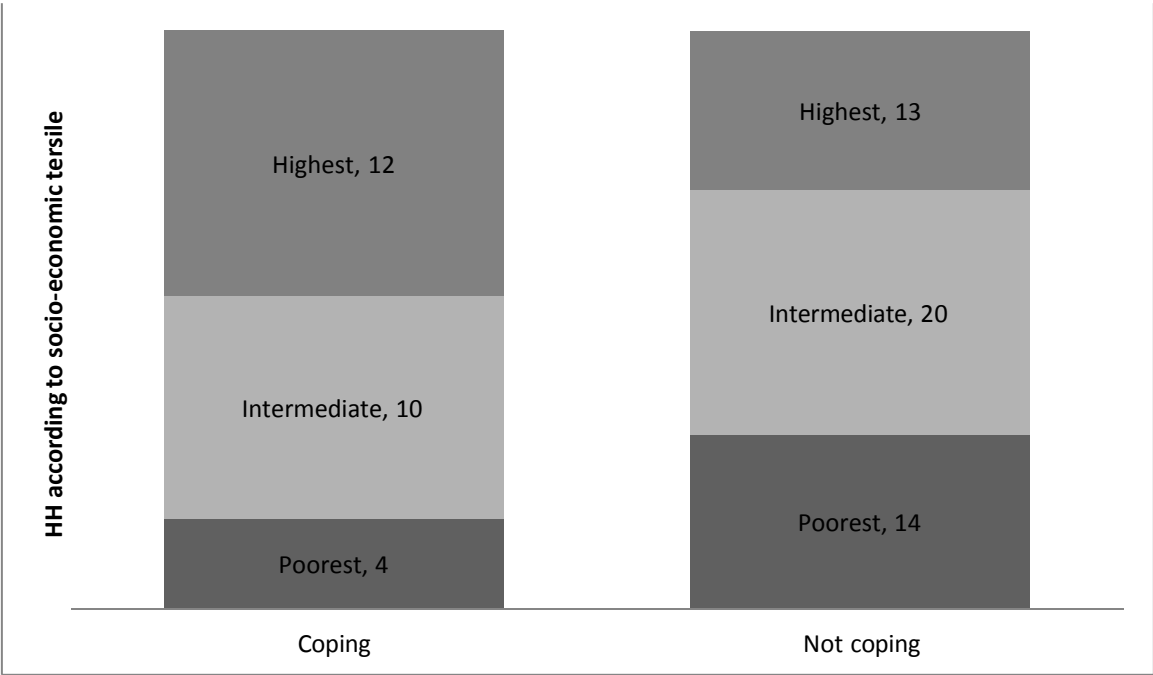
Table 3 summarises the results of the five point Likert-scale capturing the financial impact of OPP for ART at the time of follow up.

**Table 3. Financial impact on HH of OPP for ART**

<b>Financial Impact of OPP for ART</b>	<b>N (%) (n=73)</b>
<b>Minimal Impact</b>	11 (15.07)
<b>HH Manages Easily</b>	15 (20.55)
<b>HH Copes with Difficulty</b>	36 (49.32)
<b>HH Still Recovering</b>	10 (13.70)
<b>HH Survival Threatened</b>	1 (1.37)

When the data were dichotomised into “coping (comprising the first two categories in table 3) and ‘not coping’ (comprising the last three categories), 47 couples - that is nearly two-thirds (64.4%) indicated that they were not coping financially at the time of follow up. The breakdown according to socio-economic tertiles is shown in Figure 6.

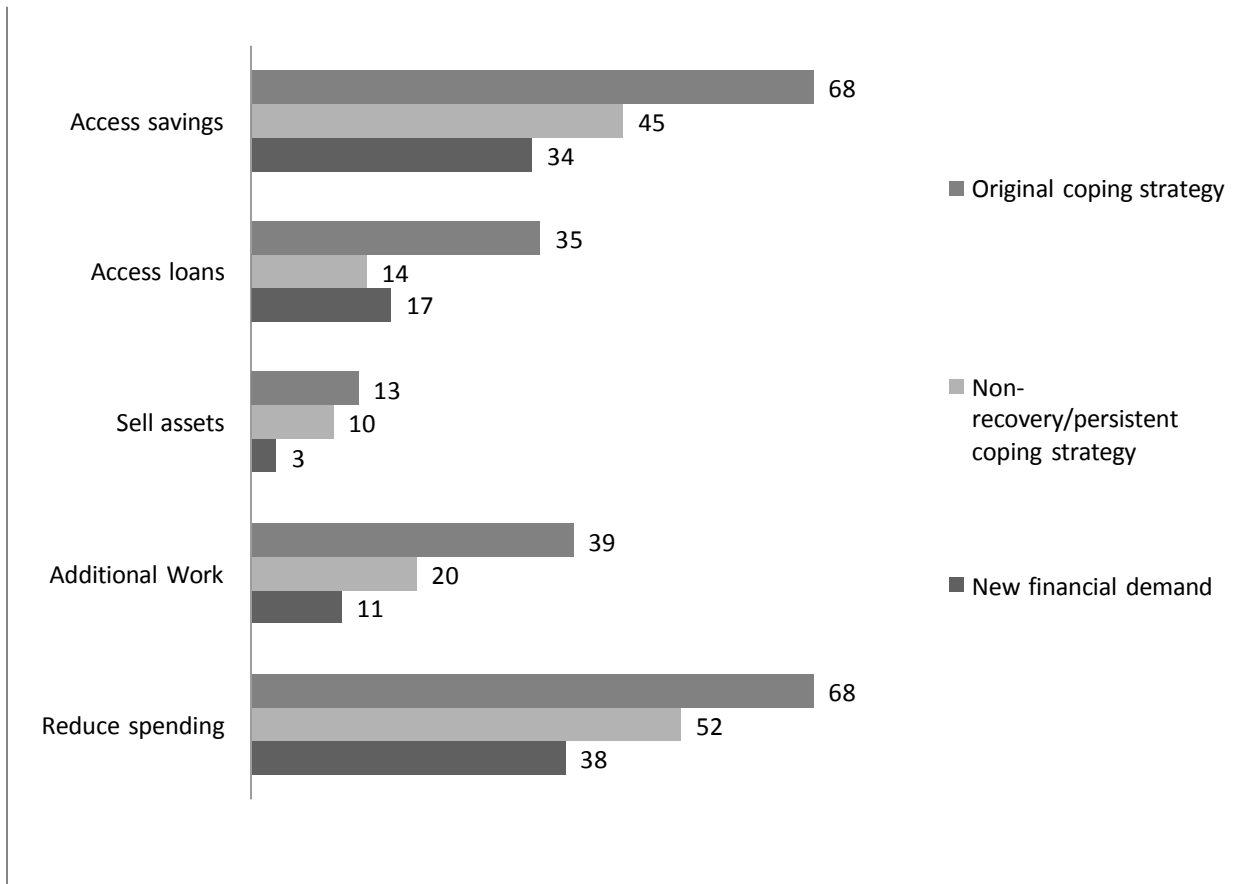
Figure 6. HH perception of coping vs non-coping with OPP for ART



**5.4 Coping strategies, recovery and new financial demands**

Figure 7 summarises the original coping strategies adopted by HH's and the persistent use of this strategy at the time of the follow-up (indicating non-recovery from this coping strategy). The graph further illustrates those who experienced simultaneous new financial demands within the coping strategy group.

**Figure 7. Original coping strategies, persistent coping strategies and new financial demands**



The majority of HHs simultaneously adopted two (43.84%) or three (47.95%) coping strategies.

**5.5. Persistent coping strategies and socio-economic tertiles**

**Figure 8. Coping strategies per socioeconomic tertile**



### **5.6. Resolved vs Unresolved Fertility Desire**

Women with unresolved fertility desire were significantly younger (38yrs; range 31-47yrs) when compared to women in the resolved group (42yrs; range 34-51yrs), ( $P < 0.0007$ ). Couples with unresolved fertility desires were equally distributed across the three socio-economic tertiles. Table 4 describes the findings pertaining to cost-recovery, coping strategies and new financial demands between the resolved and un-resolved fertility desire group. No strong differences between the two groups were apparent and the numbers were too small for meaningful statistical analysis.

**Table 4. Non recovery in HH**

<b><u>Cost Recovery</u></b>	<b>Resolved</b>	<b>Unresolved</b>
<b>Debt outstanding</b>	5 (16)*	6 (12)
<b>Unrecovered Assets</b>	2 (3)	6 (7)
<b>Unrecovered Savings</b>	20 (26)	16 (17)
<b>Still reducing spending</b>	20 (31)	18 (18)
<b>Continued Extra Work</b>	8 (12)	6 (11)
<b><u>New Financial Demand</u></b>	15 (37)	7 (20)

**\* () indicates the total number of couples incurring debt in the given group.**

## 6 **Discussion**

To the best of our knowledge this is the first study to document financial recovery, or lack thereof, among couples accessing ART through OPP.

There is a rich collection of qualitative data exploring the effects of infertility on the childless individual or couple. Furthermore there are some quantitative studies focusing on the cost of ART in various parts of the world but the majority of studies focus on the individual's perceptions pertaining to the cost of ART. While there are various health economic studies exploring OPP for various diseases and the recovery therefrom, there are no studies relating to ART and infertility.

According to our findings, only one in five couples made a full financial recovery at the time of the follow-up study (full recovery was the regaining of a sold asset, full payment of incurred debt and recovery of previously accessed savings). Forty percent of HH had been unable to settle debt they had incurred for OPP for ART. In excess of 90% couples accessed their savings to finance ART, while only one in three couples managed to recover their savings. Lastly, 77% of HH had been unable to recover a sold asset. Although several HHs had experienced new financial demands including the birth of a baby, the occurrence of continued debt or persistent loss of asset was not associated with this additional expenditure. The cumulative effect indicates that the majority of patients undergoing ART still felt lasting economic impacts secondary to OPP some three to five years after the initial health event.

Couples solely accessing savings were the most likely to recover from OPP. This is an important finding as it suggests that patients who have readily available capital to pay for the treatment are the least likely to be affected by OPP in the long term. Savings would thus be a protective factor against long term financial consequences of OPP. Our data also suggest that couples who resorted to more than one coping strategy regardless of the combination, were the least likely to recover in the long term. The employment of multiple coping strategies may thus be a predictor of poor recovery from OPP for ART.

Further coping strategies employed to offset OPP were reduction in spending and taking on additional work. Due to the current economic climate and global recession, it is hard to solely attribute the continuation of additional work and reduction in spending on ART expenses alone. Due to this confounding nature, we did not add these coping strategies in our primary quantitative evaluation of financial recovery. These methods rather provide further insight into the economic position of the HH.

Three quarters of HH's continued to reduce spending at the time of the follow-up study. The main areas where reduction in spending occurred were on non-essential items such as clothing and entertainment. This was followed by food, education, water, electricity and rent. Half of HH continued to take on additional work of which only a quarter experienced a new financial demand. The majority of employed patients increased their working hours (overtime) while some took on a second job. Unemployed couples looked for casual employment with the aim to pay for the ART.

According to additional descriptive data using self-impact scores, two in three HH reported that they were not coping financially at the time of follow up, although more HH than originally reported that they were now coping easily or were minimally affected by the OPP for ART. It was anticipated that HHs struggling to pay bills or for basic amenities and health care in the original study would be most vulnerable to lack of financial recovery. Couples from the lowest socio-economic group exhibited the poorest recovery in terms of OPP. The finding that HH who had previously coped, were now reporting difficulty in meeting basic HH needs was, however unexpected. We hypothesise that this indicates that some HH may be able to absorb the initial OPP within their resources, but enter a downward financial spiral where ultimately even daily expenditure becomes difficult. In other words, some HH coping initially could be pushed to a critical financial threshold through OPP in the long run. There was no clear correlation between the perceptions of coping or not coping as a result of OPP for ART and the ability to meet financial demands (bills, health and amenities) as we found that HHs perception of coping was variable. Both these tools were subjective markers of the impact on the HH and a self-assessment of the HH ability to cope. Some HH reported

the inability to cope but continued to meet their basic HH requirements and vice versa.

As per the original study, HH were divided into socio-economic tertiles based on per capita HH expenditure. In the original study, couples were distributed equally amongst socio-economic tertiles (poor, intermediate and rich). At follow up, couples were unevenly distributed across the original tertiles making comparison of findings more difficult. The higher rate of loss to follow up in the poorest tertile may be attributed to non-resident couples of the Western Cape Province entering the provincial health care system to gain access to the limited resource in infertility care. Of the couples that reported poor recovery, the majority were found to be in the poorest socio-economic tertile in all three areas of concern (struggling to pay bills, basic amenities and healthcare). This finding was in keeping with existing evidence that OPP for health care imposed a greater burden with long lasting economic consequences on poorer families compared to higher-income families (McIntyre et al 2006).

Half of couples in the poorest tertile who had failed to conceive indicated that they would pursue ART. One hypothesis could be that the social pressure to conceive and desire for a child is particularly high in this group of patients in keeping with other studies presented in the introduction.

Fifty two couples did not fall pregnant during the study and were divided into two groups: resolved fertility desires and unresolved fertility desires. An age profile of the two groups revealed a significant age difference with the resolved group being older (42 years) compared to the unresolved group (38 years). This was an important finding as age appeared to be a significant factor in the discontinuation of ART. Economic pressures did not, however, play determining factors in a couple's decision to accept infertility and/or adopt. To the contrary, a greater percentage of couples in the poorest tertile (50%), reported an unresolved fertility desire when compared to the other two tertiles (40%) although this was not statistically significant. This finding is contrasting to another study that demonstrated that the discontinuation of ART was secondary to the financial implications of repeat ART cycles (Klonoff-Cohen and Natarajan, 2004).

Furthermore, patients in the unresolved group were less likely to have recovered their savings. Couples from the unresolved group were twice as likely to resort to the sale of an asset to fund the ART. This again suggests the ongoing quest for a baby despite exhaustion of financial coping strategies. The sale of income generating assets was already highlighted in the literature review.

## **7 Study Limitations**

This was a small study with a 54% follow-up rate. There were many couples who were not reachable due to change of contact details. Some couples declined participation. A larger proportion of participants in the poorest socio-economic tertile were lost to follow up. This also included many of those patients who had incurred catastrophic expenditure at the time of the original study. The difference in follow up rates between the socio economic groups were, however, not statistically significant.

The financial recovery was assessed through self-report and subjective measurements using Likert scales. These findings may vary widely from couple to couple. There was no distinct correlation between perceived financial position and that of the HH's ability to pay for bills, basic amenities or health-care. These results were therefore more descriptive in nature rather than quantitative.

Additional financial demands affected fifty percent of the study population who showed poor financial recovery. Even though statistical analysis did not demonstrate an association between lack of recovery and new financial demands, the study population was very small and the possibility of a type 2 statistical error must be considered.

There was no previous research on the impact and recovery of OPP for ART in low resource settings. Therefore it was difficult to compare our findings locally, regionally or on a global level.

## **8 Conclusions**

Infertility appears to be the victim of a pervasive health administration due to its individualised and psychological nature. The WHO definition of health to include both psychological and physical well-being is often overlooked, where the psychological component suffers discrimination in a 'tangible-orientated' health system. Despite this, infertility has gained recognition globally in the last decade. ART in low resource settings remains controversial.

Tubal factor infertility is the commonest cause of the inability to conceive in Sub Saharan Africa with the treatment being ART. An argument often made is that preventative services (prevention of STI's etc) are more cost effective than curative procedures and apply to the general population. While prevention is a very important strategy, infertility is not always preventable and this approach does not assist the already infertile couple. The management of this condition should encompass a wide variety of treatments ranging from and including prevention of infertility to treatment of established pathology. Infertility treatment should be seen as a continuum of care alongside family planning and motherhood care (Pennings et al., 2009) with a carefully weighed balance between the cost effectiveness of prevention versus treatment.

Fully subsidised infertility care in low-resource settings is likely to remain unobtainable due to a high burden of disease and lack of equipment and skills. The implications however, are far reaching as documented by our findings. A systematic review documented further implications. According to this review, patients who accessed care for infertility were at risk of catastrophic expenditure for basic, traditional or ineffective medical interventions. Moreover, the review documented an overall lack of quality infertility care and the absence of financial risk protection against OPP rendering care, even if available, often unaffordable. Attention was drawn to the cumulative nature of the state of infertility care as bordering on the infringement of women's right to reproductive health (Dyer and Patel 2012).

The protection of childless couples from excessive financial risk taking and burdens

therefore requires attention. In the absence of comprehensive funding for ART, the introduction of low cost ART protocols may be one strategy to reduce the OPP. While these protocols have been successful in high-resource settings, studies are needed to assess the cost-benefit ratio and live birth outcomes in low-resource settings. Differences may be expected due to different study populations and laboratory infrastructures and standards. If found successful, low cost ART protocols could be adopted by the majority of eligible health facilities in South Africa.

This study documented a long-lasting impact of OPP for ART among all HH, where only 19% of couples were able to recover from OPP for ART three to five years after the initial health event regardless of their socio-economic tertiles. Poorest couples were disproportionately affected. ART is currently a treatment for the wealthy minority due to the lack of subsidisation even though it affects a significant proportion, tubal factor being a significant contributor, of the poor who are most disadvantaged by the current OPP system.

The unrelenting financially risk seeking behaviour have been noted by health economists. They have previously emphasized that willingness to pay does not necessarily imply the ability to pay (Russel, 1996). In fact, patients' beliefs that they are able to pay for expenses beyond their financial capacity, is what places them most at risk for unaffordable OPP.

The findings of this study can encourage policy makers to relook at the long term financial effects on the individual, family and health system and compare them to low cost and effective ART options where tubal pathology is of the biggest causes of infertility. This will be especially relevant in the context of a national health incentive policy whereby limited resources should be allocated in the most cost effective context.

Psychological counselling is imperative for both the individual and the couple. This, in conjunction with financial counselling, would provide an integral and efficient manner of assessing and assisting couples with their quest for fertility. More studies need to be conducted in order to reveal the effects of OPP on the HH and the ability of the HH to

recover. Predictors of non-recovery could then be identified and addressed at the time of patient consultation. Furthermore, if the pursuit of ART despite a poor economic position is documented in other populations, it would improve our understanding of the decision making of infertile couples, some of whom seem to take serious financial risk, in order to have a child. This risk-accepting behaviour may influence policy makers to institute some regulations to protect these vulnerable patients and HHs.

Improving access to affordable, effective and standardised infertility care is an ongoing process. The European Society of Human Reproduction and Embryology (ESHRE) have established the Task Force “Infertility in Developing Countries”. Their objectives is to raise awareness in resource restricted countries, to study the socio-cultural and financial aspects of infertility, to make infertility investigation and treatment (including ART) accessible to the majority of the population in the form of global access and to simplify and modify existing ovarian stimulation protocols and IVF procedures. Other activities have been launched by The Walking Egg Foundation and by Friends of Low Cost IVF both of which are non-profit organisations which promote accessible and affordable infertility services in developing countries.

In addition to the formation of these organisations, there has been a call to increase research aimed at the psychological, social and economic burden of infertility. A shift from more disease-focussed research to the wider reality and consequences of infertility may encourage donor agencies and governmental policy makers to endorse more funding for infertility care (Nahar 2012).

Given the high prevalence of infertility, its impact on individuals, couples and communities, the associated mental, emotional and financial consequences, and existing barriers to adequate and affordable treatment should be minimised as South Africa is moving towards the implementation of a national health system.

## **9. Recommendations**

Fully subsidised ART in low resource settings is likely to remain unobtainable. In the absence of comprehensive funding for ART, the introduction of low cost ART protocols may be one strategy to reduce the OPP in the majority of eligible health care facilities in South Africa. While these protocols have been successful in high-resource settings, studies are needed to assess the cost-benefit ratio and live birth outcomes in low- resource settings.

Couples', who require funding through OPP, should be thoroughly screened and financially counselled. Psychological counselling is imperative for both the individual and the couple. This, in conjunction with financial counselling, would provide an integral and efficient manner of assessing and assisting couples with their quest for fertility.

Further studies are required to demonstrate the effects of OPP on the HH and the ability of the HH to recover. Predictors of non-recovery could then be identified and addressed at the time of patient consultation.

There has been a move to increase research aimed at the psychological, social and economic burden of infertility thereby encouraging donor agencies and governmental policy makers to endorse more funding for infertility care (Nahar 2012).

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Appendix A

## Questionnaire for Assisted Reproductive Techniques (ART) costs and coping study

### A. Background Information

- 1. Please could you provide information on the people who live in your household?**  
 When I talk about your household, I am including all the people (particularly people who are related by blood, marriage - including common law and traditional marriage - or adoption) who live in your house for at least 2 weeks of every month and who share the same food with you.

A. Name of household Member	B. Age at next birthday	C. Sex 1 = Male; 2 = Female	D. Ethnicity	E. Place of birth	F. Relationship to head of household	G. Highest level of education	H. Employment Status	I. Belong to a medical scheme 1 = Yes; 2 = No
1 (Respondent)								
2 (Partner)								
3								
4								
5								
6								
7								
8								
9								
10								
11								
12								

CODES:

<b>D: Ethnicity</b>	<b>F: Relationship to head of household</b>	<b>G: Highest level of education</b>	<b>H: Employment Status</b>
1= African/Black	1= Head of Household	1= None	1 = Employed Full Time
2= Coloured	2= Husband/wife/ partner	2= Some primary school	2 = Self-employed (formal sector)
3= Asian/Indian	3= Son/ daughter/ step/ adopted child	3= Completed primary school	3 = Part-time/Contract/ Temporary
4= White	4= Brother/ sister / step brother/ step sister	4= Some secondary school	4 = Casual
5= Other (specify)	5= Father/ mother/ step father/ step mother	5= Completed secondary school	5 = Self-employed (Informal sector)
	6= Grandparent/ great grandparent	6 = Completed diploma	6 = Unemployed
<b>E: Place of birth</b>	7=Grandchild/ great grandchild	7 = Completed Degree	7 = Housewife
1= South Africa	8= Other relatives (e.g. in-laws or aunt/uncle)	8 = Pre-school	8 = Pensioner
2= Other (specify)	9= Non-relatives (tenants, boarders, lodgers)	9 = Other (specify)	9 = Student/ Learner/ Child
	10 = Don't know	10 = Don't know	10 = Don't know

## B. Information on Relationship

2. What is your marital status? [SINGLE MENTION]

Married	1	Single (never married)	5
Living with partner	2	'Desertion'	6
Widow/widower	3	Other (specify below)	7
Divorced or separated	4		

3. For how long have you been in a relationship with your present spouse / partner? [NUMBER OF YEARS] \_\_\_\_\_

4. For how many years have you being trying to conceive in your current relationship? \_\_\_\_\_

5. How many living children do you have from your current relationship? \_\_\_\_\_

6. How many living children do you have from any of your previous relationships? \_\_\_\_\_

7. How many living children do you have from any of your partner's / spouse's previous relationships? \_\_\_\_\_

## C. Information on Previous ART at Facility Other than GSH

8. Have you previously been treated with assisted reproductive techniques at another health facility before coming to Groc?

Yes	1	No	2	→ If no, go to Section D
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9. If yes, where did you seek care previously and in what year(s)?

Private hospital	1	Other public hospital	2
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Year(s)and the months in which previous treatment obtained \_\_\_\_\_

How many treatment cycles did you have? \_\_\_\_\_

If you have had IVF cycles in the last 12 months how many did you have and how much did that cost?

10. Can you estimate how much money you and your household personally spent on these health services [WRITE TOTAL AMOUNT IN FIGURES TO THE NEAREST RAND. TRY TO GET INFORMATION ON EACH ITEM (TOTAL CAN BE CALCULATED LATER) – IF RESPONDENT CANNOT REMEMBER INDIVIDUAL ITEMS, ASK FOR TOTAL AMOUNT BUT CHECK THAT THIS INCLUDES ALL FEES, MEDICINES AND ANY SPECIAL TESTS]?

Doctor's fee	Hospital fees	Tests	Medicines	Other	TOTAL
R	R	R	R	R	R

11. [IF COVERED BY A MEDICAL SCHEME (SEE QUESTION 11), ASK]: Did your medical scheme reimburse any of these costs, and if yes, how much did they reimburse you [WRITE TOTAL AMOUNT IN FIGURES TO THE NEAREST RAND]?

Yes	1	No	2
-----	---	----	---



R
---

12. Can you estimate any other costs you had to incur in relation to receiving treated with assisted reproductive techniques at facilities other than GSH [WRITE TOTAL AMOUNT IN FIGURES TO THE NEAREST RAND. TRY TO GET INFORMATION ON EACH ITEM (TOTAL CAN BE CALCULATED LATER) – IF RESPONDENT CANNOT REMEMBER INDIVIDUAL ITEMS, ASK FOR TOTAL AMOUNT BUT CHECK THAT THIS INCLUDES ALL ITEMS]?

Transport costs to health care facility	Loss of income due to time off work	Other	TOTAL
R	R	R	R

13. How did you manage to pay for these costs [MULTIPLE MENTION]?

1. Did you have to use money you had previously saved?	Yes = 1	No = 2
1a If yes, did you use up all your savings?	Yes = 1	No = 2
2. Did you have to borrow money? [If no, go to sub-question 3]	Yes = 1	No = 2
2a If yes, how much did you borrow? [specify amount]	R	
2b Who did you borrow money from?	Code	If other, specify

Relative = 1 Friend = 2 Employer = 3 Bank = 4 Other money lender = 5 Other [specify] = 6		
<b>2c</b> Did you have to pay interest on this loan?	Yes = 1	No = 2
<b>2d</b> Is this loan fully repaid yet?	Yes = 1	No = 2
<b>3.</b> Did you receive financial assistance (a gift rather than a loan)?	Yes = 1	No = 2
<b>3a If yes</b> , who did you receive financial assistance from? Relative = 1 Friend = 2 Employer = 3 Other [specify] = 4	<b>Code</b>	<b>If other, specify</b>
<b>4.</b> Did you have to sell any assets?	Yes = 1	No = 2
<b>4a If yes</b> , what type of assets? Jewellery = 1 Household goods (e.g. TV) = 2 Car = 3 Other [specify] = 4	<b>Code</b>	<b>If other, specify</b>
<b>5.</b> Did you have to reduce spending on other household items?	Yes = 1	No = 2
<b>5a If yes</b> , what household items did you have to reduce spending on? Food = 1 Rent (e.g. move to cheaper area) = 2 Clothing = 3 Education = 4 Entertainment = 5 Other [specify] = 6	<b>Code</b>	<b>If other, specify</b>
<b>6.</b> Did you or other members of your household have to take on extra work to try to generate extra income?	Yes = 1	No = 2

14. Why did you decide to stop treatment at the other facility and seek care at Groote Schuur?

Could no longer afford it	1	Better quality of care at GSH	2
Other (specify)			3

**D. Information on previous ART at Groote Schuur**

15. Is this your first cycle of ART at Groote Schuur?

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
--------------------------	--------------------------	--------------------------	--------------------------

↓

If yes, go to Question 20

16. [IF NO, ASK] how many previous cycles have you had at Groote Schuur and in what month and year did these cycles take place? If you have had IVF cycles in the last 12 months, how many have you had and what was there cost?

17. What was the outcome of each of these cycles?

.....

.....

18. Can you estimate how much money you and your household personally spent on these health services [WRITE TOTAL AMOUNT IN FIGURES TO THE NEAREST RAND. TRY TO GET INFORMATION ON EACH ITEM (TOTAL CAN BE CALCULATED LATER) – IF RESPONDENT CANNOT REMEMBER INDIVIDUAL ITEMS, ASK FOR TOTAL AMOUNT BUT CHECK THAT THIS INCLUDES ALL FEES, MEDICINES AND ANY SPECIAL TESTS]?

Doctor's fee	Hospital fees	Tests	Medicines	Other	TOTAL
R	R	R	R	R	R

19. [IF COVERED BY A MEDICAL SCHEME (SEE QUESTION 1G), ASK]: **Did your medical scheme reimburse any of these costs, and if yes, how much did they reimburse you** [WRITE TOTAL AMOUNT IN FIGURES TO THE NEAREST RAND]?

Yes	1	No	2
-----	---	----	---



R
---

20. **Can you estimate any other costs you had to incur** [WRITE TOTAL AMOUNT IN FIGURES TO THE NEAREST RAND. TRY TO GET INFORMATION ON EACH ITEM (TOTAL CAN BE CALCULATED LATER) – IF RESPONDENT CANNOT REMEMBER INDIVIDUAL ITEMS, ASK FOR TOTAL AMOUNT BUT CHECK THAT THIS INCLUDES ALL ITEMS]?

Transport costs to health care facility	Loss of income due to time off work	Other	TOTAL
R	R	R	R

21. **How did you manage to pay for these costs** [MULTIPLE MENTION]?

1. Did you have to use money you had previously saved?	Yes = 1	No = 2
<b>1a</b> If yes, did you use up all your savings?	Yes = 1	No = 2
2. Did you have to borrow money? [If no, go to sub-question 3]	Yes = 1	No = 2
<b>2a</b> If yes, how much did you borrow? [specify amount]	R	
<b>2b</b> Who did you borrow money from?  Relative = 1 Friend = 2 Employer = 3  Bank = 4 Other money lender = 5 Other [specify] = 6	<b>Code</b>	<b>If other, specify</b>
<b>2c</b> Did you have to pay interest on this loan?	Yes = 1	No = 2
<b>2d</b> Is this loan fully repaid yet?	Yes = 1	No = 2
3. Did you receive financial assistance (a gift rather than a loan)?	Yes = 1	No = 2
<b>3a</b> If yes, who did you receive financial assistance from?	<b>Code</b>	<b>If other,</b>

Relative = 1 Friend = 2	Employer = 3 Other [specify] = 4		<b>specify</b>
<b>4.</b> Did you have to sell any assets?		Yes = 1	No = 2
<b>4a</b> <i>If yes</i> , what type of assets?		<b>Code</b>	<b>If other, specify</b>
Jewellery = 1 Household goods (e.g. TV) = 2	Car = 3 Other [specify] = 4		
<b>5.</b> Did you have to reduce spending on other household items?		Yes = 1	No = 2
<b>5a</b> <i>If yes</i> , what household items did you have to reduce spending on?		<b>Code</b>	<b>If other, specify</b>
Food = 1 Rent (e.g. move to cheaper area) = 2 Clothing = 3	Education = 4 Entertainment = 5 Other [specify] = 6		
<b>6.</b> Did you or other members of your household have to take on extra work to try to generate extra income?		Yes = 1	No = 2

## E. Information on current ART at Groote Schuur

22. I now want to ask you about your current cycle of ART. What was the indication for your most recent ART cycle? [MULTIPLE MENTION]

Tubal factor ('blocked tubes')	1	Unexplained infertility	6
Sperm problem	2	Failure of other infertility interventions	7
Failure to ovulate	3	Indication not known by respondent	8
Age-related fertility problem	4	Other (please specify below)	9
Endometriosis	5		

23. Can you estimate how much money you and your household personally spent on this cycle of ART [WRITE TOTAL AMOUNT IN FIGURES TO THE NEAREST RAND. TRY TO GET INFORMATION ON EACH ITEM (TOTAL CAN BE CALCULATED LATER) – IF RESPONDENT CANNOT REMEMBER INDIVIDUAL ITEMS, ASK FOR TOTAL AMOUNT BUT CHECK THAT THIS INCLUDES ALL FEES, MEDICINES AND ANY SPECIAL TESTS]?

Doctor's fee	Hospital fees	Tests	Medicines	Other	TOTAL
R	R	R	R	R	R

24. [IF COVERED BY A MEDICAL SCHEME (SEE QUESTION 11), ASK]: Did your medical scheme reimburse any of these costs, and if yes, how much did they reimburse you [WRITE TOTAL AMOUNT IN FIGURES TO THE NEAREST RAND]?

Yes	1	No	2
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R
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25. How much does it cost you to travel here today [e.g. taxi, bus and/or train fare or petrol costs - TOTAL AMOUNT IN FIGURES TO THE NEAREST RAND]?

R
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**31. Many couples undergoing ART experience this treatment as stressful. By this we mean that the treatment is putting emotional, physical and financial demands on you, which are over and above the demands that you face in your daily life, and which you may find difficult to cope with. How stressful was the current ART cycle for you personally, if you consider all these demands? Please choose one of the following 5 answers:**

	Male Respondent	Female respondent
1. not at all stressful		
2. a little bit stressful		
3. moderately stressful		
4. quite a bit stressful		
5. extremely stressful		

**32. How much did the financial demands of the ART treatment contribute to this overall experience of stress?**

	Male Respondent	Female respondent
1. not at all		
2. a little bit		
3. moderately		
4. quite a bit		
5. extremely		

## F. Household Socio-Economic Information

### 33. Which type of dwelling does your household occupy?

<i>Formal</i>	House or formal structure on a separate stand	1
	Flat in a block of flats	2
	Town/cluster/semi-detached house (simplex/duplex or triplex)	3
	Unit in retirement village	4
	Room/flatlet in main dwelling	5
	House/flat/room, in backyard	6
<i>Informal</i>	Informal dwelling/shack, NOT in backyard	7
	Informal dwelling/shack, IN the backyard of a formal house	8
<i>Traditional</i>	Traditional dwelling/hut/structure made of traditional materials	9
<i>Other</i>	Specify:	10

### 34. What is the main material of the house's walls?

Brick & Plaster/finished	1	Wood	6
Bare brick/cement block	2	Asbestos	7
Mud and cement	3	Wattle and daub	8
Mud	4	Plastic/cardboard	9
Corrugated iron/zinc	5	Other (specify)	10

### 35. What is the main material of the house's roof?

Tiles	1	Asbestos	4
Corrugated iron/zinc	2	Plastic/cardboard	5

Thatching	3	Other (specify)	6
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- 36. How many rooms, including kitchens, does your home have? [EXCLUDE BATHROOMS, SHEDS, GARAGES, STABLES ETC. UNLESS PERSONS ARE LIVING IN THEM]**


- 37. What is the main source of drinking water for members of your household? [SINGLE MENTION]**

Piped water in dwelling	1	Water carrier/tanker	5
Piped water in yard	2	Borehole/well	6
Public tap	3	Dam/river/stream/spring	7
Rain-water tank	4	Other (specify)	8

- 38. What type of toilet facility does your household have? [SINGLE MENTION]**

Flush toilet (connected to sewerage)	1	Pit latrine	4
Flush toilet (septic tank)	2	Bucket toilet	5
Chemical toilet	3	No facility/bush/field	6

- 39. What is the main source of energy for cooking in your household? [SINGLE MENTION]**

Electricity	1	Wood	5
Solar energy	2	Coal	6
Gas	3	Animal dung	7
Paraffin	4	Other (specify)	8

- 40. I am going to read out a list of things that are found in some households and I would like you to tell me whether you have them (currently working) in your household or not.**

1. Ordinary (Telkom) telephone	1	2	←
2. <b>If yes</b> , Is this prepaid? (Code 1 for prepaid; i.e. 2 for account)	1	2	
3. Cell phone	1	2	
4. <b>If yes</b> , Is this prepaid? (Code 1 for prepaid; 2 for contract; 1 and 2 for both prepaid and contract)			
5. Personal computer at home	1	2	
6. An Internet connection on a computer	1	2	
7. Fridge	1	2	
8. Car / truck / bakkie	1	2	←
9. <b>If yes</b> , how old is the newest car / truck / bakkie in your household since the date of manufacture [SPECIFY AGE IN YEARS]			<b>If yes, go to 9</b>

41. How many people in this household currently receive the following grants or other kinds of income from government? [CODE '0' IF NO-ONE IS RECEIVING THAT TYPE]

<i>Income category</i>		<i>No. of people in household receiving...</i>
Unemployment Insurance (UIF)		
Worker's Compensation		
Grants	State Old Age pension	
	Disability grant	
	Child Support Grant	(No. of children)
	Foster Care Grant	(No. of children)
	Care Dependency	(No. of children)
War Veteran's Grant		
Other (specify)		

42. In general, how much does your household usually spend in a month? [STATE AMOUNT IN RAND]

R
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43. In general, how much does your household usually spend:

Item	Amount (Rands)
------	----------------

In a month on groceries (e.g. food, cleaning supplies, cigarettes, alcohol etc.)	
In a month on rent	
In a month on electricity, water and other payments to the council	
In a month on any other types of fuel to use in the house for cooking or heating (wood, paraffin etc.)	
In a month on telephones (landline/Telkom and/or cellphones)	
In a month on transport (petrol if you own a car and/or taxis, buses, trains or other public transport)	
In a month on clothes	
In a month on entertainment (movies, eating out at a restaurant etc.)	
In a month on any other regular household payments (e.g. hire purchase or shop account payments, insurance, tv rental, contributions to religious organisations etc.)	
In a year on education fees, uniforms and books (e.g. school for children or university for self or other adult dependent)	
In a year on any other items that you do not have to pay for on a monthly basis (e.g. holidays)	

Appendix B

## Questionnaire for Assisted Reproductive Techniques (ART) costs and coping study

### A. Background Information

1. Has anything changed in the composition of your household? If yes, please indicate below. (If there are any additional people living with you now or if anyone has moved out of your household)

A. Name of household member	B. Age at next birthday	C. Sex 1 = Male; 2 = Female	D. Ethnicity	E. Place of birth	F. Relationship to head of household	G. Highest level of education	H. Employment Status	I. Belong to a medical scheme 1 = Yes; 2 = No
1 (Respondent)								
2 (Partner)								
3								
4								
5								
6								
7								
8								
9								
10								
11								
12								

CODES:

<b>D: Ethnicity</b>	<b>F: Relationship to head of household</b>	<b>G: Highest level of education</b>	<b>H: Employment Status</b>
1= African/Black	1= Head of Household	1= None	1 = Employed Full Time
2= Coloured	2= Husband/wife/ partner	2= Some primary school	2 = Self-employed (formal sector)
3= Asian/Indian	3= Son/ daughter/ step/ adopted child	3= Completed primary school	3 = Part-time/Contract/ Temporary
4= White	4= Brother/ sister / step brother/ step sister	4= Some secondary school	4 = Casual
5= Other (specify)	5= Father/ mother/ step father/ step mother	5= Completed secondary school	5 = Self-employed (Informal sector)
	6= Grandparent/ great grandparent	6 = Completed diploma	6 = Unemployed
<b>E: Place of birth</b>	7=Grandchild/ great grandchild	7 = Completed Degree	7 = Housewife
1= South Africa	8= Other relatives (e.g. in-laws or aunt/uncle)	8 = Pre-school	8 = Pensioner
2= Other (specify)	9= Non-relatives (tenants, boarders, lodgers)	9 = Other (specify)	9 = Student/ Learner/ Child
	10 = Don't know	10 = Don't know	10 = Don't know

**Please explain the reasons for the change in the household.**

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**2. Has your marital status changed since the previous study?**

YES	NO
-----	----



Same relationship	
Now married	
Separated	
Divorced	
Separated and now living with new partner	
Divorced and now living with new partner	

### C. Conception and Outcome since Intervention

3. **Current Fertility Status:** Since your participation in the last study, did you fall pregnant?

YES	NO
-----	----



**Pregnancy**

As a result of study cycle	
In a subsequent cycle	
Spontaneous Conception	



**What was the outcome of this pregnancy?**

Ongoing Pregnancy	
Live birth (Singleton/ Multiple)	
Pregnancy Loss	



**Infertility**

<b>Resolved</b>	I will no longer undergo ART despite not conceiving	
	I am/will pursue the avenue of adoption	
<b>Repeat Cycle</b>	I am currently undergoing repeat ART	
	I will continue with ART in the future	

#### D. Information on further ART at Groote Schuur

4. Since your participation in this study, have you spent more money on infertility treatment?

No	1	Yes	2
----	---	-----	---



If no, skip questions 4 - 8 and go to Question 9

5. Where did you receive this treatment?

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6. What cycle was used?

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7. Can you estimate how much money you and your household personally spent on these health services [WRITE TOTAL AMOUNT IN FIGURES TO THE NEAREST RAND. TRY TO GET INFORMATION ON EACH ITEM (TOTAL CAN BE CALCULATED LATER) – IF RESPONDENT CANNOT REMEMBER INDIVIDUAL ITEMS, ASK FOR TOTAL AMOUNT BUT CHECK THAT THIS INCLUDES ALL FEES, MEDICINES AND ANY SPECIAL TESTS]?

Doctor's fee	Hospital fees	Tests	Medicines	Other	TOTAL
R	R	R	R	R	R

8. [IF COVERED BY A MEDICAL SCHEME (SEE QUESTION 1G), ASK]: Did your medical scheme reimburse any of these costs, and if yes, how much did they reimburse you [WRITE TOTAL AMOUNT IN FIGURES TO THE NEAREST RAND]?

Yes	1	No	2
-----	---	----	---



R
---

9. **Can you estimate any other costs you had to incur** [WRITE TOTAL AMOUNT IN FIGURES TO THE NEAREST RAND. TRY TO GET INFORMATION ON EACH ITEM (TOTAL CAN BE CALCULATED LATER) – IF RESPONDENT CANNOT REMEMBER INDIVIDUAL ITEMS, ASK FOR TOTAL AMOUNT BUT CHECK THAT THIS INCLUDES ALL ITEMS]?

Transport costs to health care facility	Loss of income due to time off work	Other	TOTAL
R	R	R	R

10. **During the past 12 months, how often did it happen that you:**

	Never = 1	Not very often = 2	Fairly often = 3	Very often = 4	Can't really say / don't know = 5
... had trouble paying the bills?					
... did not have enough money to buy food, clothes or other things your household needed?					
... did it happen that you did not have enough money to pay for health care (other than for your infertility treatment)					

11. **How would you describe the financial impact of your ART (underwent during the previous study) at this moment in time on the household?** [SINGLE MENTION]

Minimal	1
Household managed easily	2
Household copes, but with difficulty	3

Burden that the household is still recovering from / struggling with	4
Household unable to cope, and its survival is threatened	5

**12. How would you describe the financial impact of all the ART (including before and after the study) at this moment in time on the household? [SINGLE MENTION]**

Minimal	1
Household managed easily	2
Household copes, but with difficulty	3

Burden that the household is still recovering from / struggling with	4
Household unable to cope, and its survival is threatened	5

**13. Many couples undergoing ART experience financial stress. How stressful was the current ART cycle for you personally, with regard to your financial situation? Please choose one of the following 5 answers:**

	Male Respondent	Female respondent
6. not at all stressful		
7. a little bit stressful		
8. moderately stressful		
9. quite a bit stressful		
10. extremely stressful		

## F. Household Socio-Economic Information

I'D NOW LIKE TO ASK YOU ABOUT YOUR HOUSEHOLD'S STANDARD OF LIVING.

14. Has your type of dwelling changed? (Please circle the appropriate answer)

YES	NO
-----	----

15. Which type of dwelling does your household now occupy?

<i>Formal</i>	House or formal structure on a separate stand	1
	Flat in a block of flats	2
	Town/cluster/semi-detached house (simplex/duplex or triplex)	3
	Unit in retirement village	4
	Room/flatlet in main dwelling	5
	House/flat/room, in backyard	6
<i>Informal</i>	Informal dwelling/shack, NOT in backyard	7
	Informal dwelling/shack, IN the backyard of a formal house	8
<i>Traditional</i>	Traditional dwelling/hut/structure made of traditional materials	9

16. How many rooms, including kitchens, does your home have? [EXCLUDE BATHROOMS, SHEDS, GARAGES, STABLES ETC. UNLESS PERSONS ARE LIVING IN THEM]


17. What is the main source of drinking water for members of your household? [SINGLE MENTION]

Piped water in dwelling	1	Water carrier/tanker	5
Piped water in yard	2	Borehole/well	6
Public tap	3	Dam/river/stream/spring	7
Rain-water tank	4	Other (specify)	8

18. What type of toilet facility does your household have? [SINGLE MENTION]

Flush toilet (connected to sewerage)	1	Pit latrine	4
Flush toilet (septic tank)	2	Bucket toilet	5
Chemical toilet	3	No facility/bush/field	6

19. What is the main source of energy for cooking in your household? [SINGLE MENTION]

Electricity	1	Wood	5
Solar energy	2	Coal	6
Gas	3	Animal dung	7
Paraffin	4	Other (specify)	8

20. I am going to read out a list of things that are found in some households and I would like you to tell me whether you have them (currently working) in your household or not.

	Yes	No
1. Ordinary (Telkom) telephone	1	2
2. <b>If yes</b> , Is this prepaid? (Code 1 for prepaid; i.e. 2 for account)	1	2
3. Cell phone	1	2
4. <b>If yes</b> , Is this prepaid? (Code 1 for prepaid; 2 for contract; 1 and 2 for both prepaid and contract)		
5. Personal computer at home	1	2
6. An Internet connection on a computer	1	2
7. Fridge	1	2

If no, go to 3

8. Car / truck / bakkie	1	2
9. <b>If yes</b> , how old is the newest car / truck / bakkie in your household since the date of manufacture [SPECIFY AGE IN YEARS]		

21. How many people in this household currently receive the following grants or other kinds of income from government? [CODE '0' IF NO-ONE IS RECEIVING THAT TYPE]

<i>Income category</i>		<i>No. of people in household receiving...</i>
Unemployment Insurance (UIF)		
Worker's Compensation		
Grants	State Old Age pension	
	Disability grant	
	Child Support Grant	(No. of children)
	Foster Care Grant	(No. of children)
	Care Dependency	(No. of children)
	War Veteran's Grant	
Other (specify)		

If yes, go to 9

22. In general, how much does your household usually spend in a month? [STATE AMOUNT IN RAND]

R

23. In general, how much does your household usually spend:

Item	Amount (Rands)
In a month on groceries (e.g. food, cleaning supplies, cigarettes, alcohol etc.)	
In a month on rent	
In a month on electricity, water and other payments to the council	
In a month on any other types of fuel to use in the house for cooking or heating (wood, paraffin etc.)	
In a month on telephones (landline/Telkom and/or cellphones)	

In a month on transport (petrol if you own a car and/or taxis, buses, trains or other public transport)	
In a month on clothes	
In a month on entertainment (movies, eating out at a restaurant etc.)	
In a month on any other regular household payments (e.g. hire purchase or shop account payments, insurance, tv rental, contributions to religious organisations etc.)	
In a year on education fees, uniforms and books (e.g. school for children or university for self or other adult dependent)	
In a year on any other items that you do not have to pay for on a monthly basis (e.g. holidays)	

**24. Did you access your savings to fund the ART? (Tick in the correct box)**

YES	NO
-----	----

Did you access your savings at a later point

YES	NO
-----	----

**25. Have you recovered your savings? (Money put away)**

YES	ALMOST	VERY LITTLE	NOT AT ALL
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**26. Did you borrow money to fund the ART?**

YES	NO
-----	----

Did you borrow money at a later point?

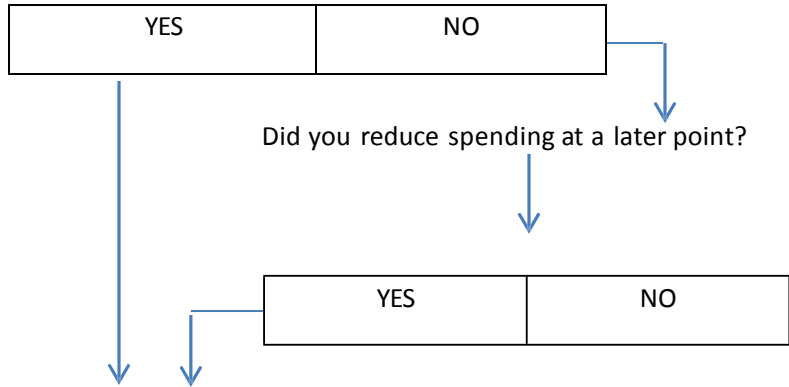
YES	NO
-----	----

**27. Have you managed to pay back the money?**

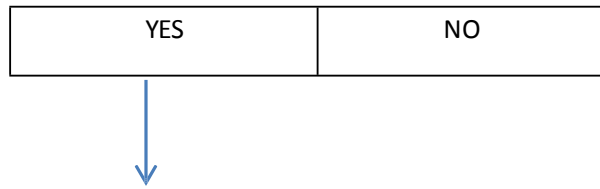
YES	NO
-----	----

**28.**

**29. Did you reduce spending?**



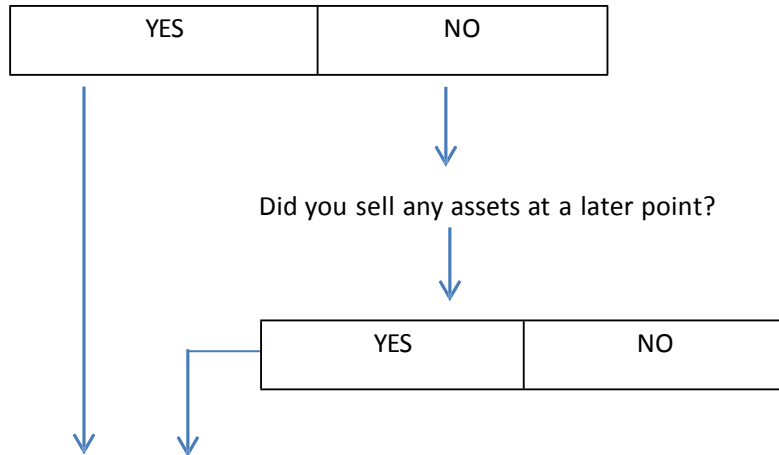
**30. Are you still reducing your spending?**



**31. On what are you still reducing your spending?**

Clothing	Food	Entertainment	Education	Rent	Water and Electricity	Existing Children
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**32. Did you sell any asset/s?**



**33. Have you acquired the asset/s again?**



**34. Did you take on extra work?**

YES	NO
-----	----

Did you take on work at a later point?

YES	NO
-----	----

**35. Are you still doing extra work now?**

YES	NO
-----	----

## **Appendix C**

### **Patient Information Sheet**

#### **Follow-up of The Assisted Reproductive Technologies (ART) Cost Study**

Researchers at Groote Schuur Hospital and the Faculty of Health Sciences would like to conduct a follow-up study of our earlier study on out-of pocket payment for ART.

Thank you for your participation in our previous study. We have learnt a great deal from you and the many other patients. We could be grateful if you would allow us to interview you once again about your experiences since you participated in our previous study.

The aim of this study is to determine to what extent patients undergoing IVF at Groote Schuur Hospital Infertility Clinic have recovered from the costs of their ART treatment and the methods adopted in this recovery. We would also like to explore further what impact the cost of treatment has had on you, your family and in your daily lives and for how long this impact was felt. No studies of this nature have been carried out before. We hope that the findings of this study, in conjunction with the previous study, will allow us to better prepare patients for IVF treatment in future, and perhaps influence the hospital/medical aids to provide better funding for ART. In addition, this study will assist one of the researchers to further their studies by obtaining a Master of Medicine (MMed) degree.

We would like to include both you and your partner in this follow-up study, but if for any reason either of you decline, you or your partner can participate on their own.

We would be appreciative if you could spare about 30 minutes of your time to answer a very similar questionnaire to the one you previously answered. All the information collected will be confidential, and when we present the findings of this research it will not be possible to identify you or anything you have shared with the interviewer. You are not obliged to answer all the questions. If you feel uneasy at any point during the interview, you may decline to answer the question. The interview will be carried out by a person who is not directly involved with your treatment. Therefore, anything you disclose about your financial means will in no way influence your treatment or the cost of your treatment.

Owing to the sensitive nature of IVF, you or your partner may experience emotional distress during the interview. If this occurs we will counsel you at the end of the interview, but should this not be sufficient we will refer you to a social worker or a mental health professional.

Unfortunately, we are not able to reimburse you for taking part in the study but we can reimburse you for the cost of travel to and from the hospital.

If at any stage you have any questions about the research or you would like to contact us regarding the study, you may phone or write to us at the Groote Schuur Hospital Infertility Clinic. You can address the letter to Dr Vinoos or Professor Dyer. Alternatively you may contact the Human Ethics Committee in room E52-24 Groote Schuur Hospital Old Main Building or phone 021-406 6338.

**Appendix D**

**Patient Consent Form**

**Follow-up of The Assisted Reproductive Technologies Cost Study**

I/We, ..... the undersigned, consent to participate in this study and agree to be interviewed in the knowledge that everything I say will be kept confidential and will not be accessible to anybody other than the members of the research team.

I acknowledge that I have received and read the information sheet.

Date: .....

Signature: (Woman) .....

Signature: (Man) .....

Witness: .....