Out-of-Pocket Payment for Assisted Reproductive Techniques in the public health sector in South Africa - How do Households Cope?

Dr Kerry Anne Sherwood

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Supervisor: Prof.S Dyer

Department Of Obstetrics and Gynaecology,
Groote Schuur Hospital

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Declaration

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Abstract

Title: Out-of –pocket payments for ART in the public health sector in South Africa: how do households cope?

Introduction: In South Africa assisted reproductive techniques (ART) are poorly covered by health insurances or government funding thereby often inflicting out-of-pocket payment (OPP) on patients. This can create treatment barriers or high financial burdens for households, with unknown consequences of the latter. This is the first study from South and sub-Saharan Africa which explores the impact of ART-related OPP on households.

Methods: The study was undertaken at Groote Schuur Hospital, Cape Town, where ART is subsidized but patients have to contribute to the cost of treatment. Eighty six consecutive IVF/ICSI cycles were prospectively analysed through patient interviews. Data included socio-demographic, economic, and infertility information, emotional and financial stress among participants, as well as coping and financial strategies adopted by households. In keeping with international recommendations, catastrophic expenditure was defined as a direct cost of all ART cycles in the last 12 months equal to or exceeding 40% of the annual non-food household expenditure.

Results: The majority of couples were married and childless in union. The average household size was 3.4 people with an average monthly expenditure of R11 872. The mean direct cost per ART cycle was R11 527. According to definition, 35% of households experienced catastrophic health care expenditure. Approximately 40% of household struggled to pay bills and meet basic needs. Nearly 5% of household felt their survival threatened. The most frequently used financial strategies were accessing savings, borrowing money and reducing household expenditure on luxury and non-luxury (food, rent, schooling) items. Nearly 50% of couples took on extra work and one in ten households sold assets. Gender differences were observed in treatment-related emotional and financial stress but were not statistically significant.

Conclusion: ART created a large financial burden and caused catastrophic costs in 35% of couples. Couples adopted different financial strategies, many of which have long-term impact. These findings are relevant for patient counselling and highlight problems in reproductive health funding in South Africa.

1. Introduction

1.1 Infertility and Childlessness in Developing Countries

In 1978, the world's first "test tube baby", Louise Brown, was born via in vitro fertilization. Thirty years on and more than 5 million births later, this reproductive technique still remains largely inaccessible to many infertile couples in poorer communities and countries.

Infertility is a worldwide reproductive health problem affecting 15% of reproductive-aged couples (Vayena et al, 2002). A global study using data from 47 Demographic and Health Surveys (DHS) in low-resource countries, 26 being in Africa, estimated that more than 186 million ever-married women of reproductive age (15-49 years) were infertile. This number comprises primary infertility (infertility without history of previous pregnancy) and secondary infertility (infertility after earlier pregnancy). This quantity represented approximately a quarter of ever-married women of reproductive age in these countries (Rutstein et al, 2004).

The enormity of the infertility problem in Sub-Saharan Africa is more serious than other parts of the world. In Southern and central Africa, almost half of fertile men have a history of having a sexually transmitted infection and two thirds of infertile women have tubal pathology from sterilizing sexually transmitted diseases. In comparison to the rest of the world, this infection rate is two to four times higher (Nachtigall, 2006; Vayena et al, 2002). It is also important to point out that not all of these infections are sexually acquired: 30 % of women of reproductive age will also contract infections from postpartum sepsis, post abortive sepsis and iatrogenic infections causing secondary infertility. Tubal infertility could be prevented through early detection and treatment of sexually transmitted diseases (Nachtigall, 2006 and Inhorn, 2003). Male factor infertility contributes to half of all cases of sub fertility globally (Irvine, 1998). It is now known, through the advances in genetics, that a significant proportion of male factor infertility is caused by genetic abnormalities and is thus unpreventable and difficult to treat (Maduro and Lamb, 2002).

Tubal damage secondarily to sepsis is the most severe therefore decreasing the success of reconstructive tubal surgery. In these cases ART has been shown to be the most effective and cost-effective treatment (Ombelet, 2009). In the case of severe male factor infertility, ART has also proven to be beneficial over more conservative interventions such as intra-uterine inseminations (Inhorn, 2009).

In African countries fertility and children are highly desired and parenthood is culturally compulsory. As a result, infertility is associated with negative psychosocial and potentially life threatening consequences especially for women (Dyer et al, 2004; Dyer et al, 2005). These include: marital instability, domestic violence, neglect, ostracism and stigmatization. Pregnancy is both physical and visible and women are blamed for reproductive failures even if the cause is male factor infertility (Inhorn, 2009).The DHS survey (2004) showed that barren women were more likely to be divorced or separated, especially in Latin America. In an attempt to have children, childless women are more likely to have been married more than once and men may resort to polygamy (Inhorn, 2009). Infertile women are more exposed to domestic violence and may suffer physical, emotional and verbal abuse from their husbands as well as the extended family (Nachtigall, 2006). Evidence has shown that infertile women have a higher chance of being infected with the HIV virus than fertile women (Rutstein et al, 2004).Childlessness can result in economic burdens. Children ensure financial security for families and secure old age welfare (Inhorn et al, 2003). Women who have been abandoned may be forced into prostitution as a way of financial survival (Inhorn, 2009). In the Middle East and Sub-Saharan Africa, emerging evidence has revealed that infertile women face social isolation and scorn. They may even be turned away from life rituals that involve femininity, fertility and children (Inhorn, 1994, 1996, 2009). Although adoption remains an alternative to infertility, in many cultures this is taboo and goes against many religious and cultural beliefs (Bharadwaj, 2003; Inhorn, 2006).

The psychological effects of male infertility are less well described. Male factor infertility still remains buried deep within communities as the stigmatization is related to issues around sexuality and virilism. Male infertility, like female infertility, impacts on personhood, marriage and community relations. Men, in the hope to conceive, expose themselves to genital surgeries and ineffective traditional or medical medications. (Inhorn, 2002)

In summary, in developing countries, infertility causes marital, economic, social and physical adverse effects, affecting the basic rights of a person. Infertility is a chronic illness and social condition which affects a person's security and happiness. It is a condition that should be treated.

Infertility has been assessed as a human rights issue and has gained recognition at the International Conference on Population and Development held in Cairo 15 years ago. At this conference an agenda was formed which stated that infertile men and women should have access to comprehensive infertility treatment as a reproductive

'right", but this is still to be achieved by millions of infertile couples in Sub-Saharan Africa.

1.2 Access to Health Care

Driven by the need to conceive, many infertile couples or women will seek help from the medical sector, both traditional and biomedical. In the absence of conception this search continues over long periods of time. According to studies from several African countries, infertility is either the leading cause or a very common reason for gynaecological consultations (Bergstrom, 1992; Inhorn and Buss, 1993; Okonofua, 1996; Sundby et al, 1998; Stewart-Smythe and Van Iddekinge, 2003). This data suggests that due to the chronic nature of infertility these couples may face considerable health cost.

In many African countries ART and other effective infertility treatments are not available or are difficult to access. Frequently the couples only contact with treatment is through the private sector. Furthermore, ART is usually not covered by private or social health insurance or general tax funds resulting in out-of-pocket payments (OPP) by the patients to finance infertility treatment. In South Africa, infertility treatment can be accessed through both the private and public sectors, although treatment facilities in the public sector are limited. The public health sector is structured into primary, secondary and tertiary level care. This system offers health care to all patients who cannot afford private health care. Patients, who can afford private health care due to medical insurance or monthly income above a certain level, can still enter public health sector but pay higher fees when compared to patients with no medical insurance or are of a lower income.

There are currently 12-15 ART centres in South Africa. The majority of these centres are in the private health sector, and most medical aid schemes do not fund ART. The Reproductive Medicine Unit at Groote Schuur Hospital is currently the only centre in South Africa providing comprehensive tertiary level infertility care within the public sector. All couples appropriately referred can access infertility treatment, and ART is available within this service. Although subsidised by the hospital, ART is, however, not free .Patients have to contribute to the cost of their treatment and meet the cost of their infertility drugs that are not on hospital code due to budgetary constraints. The average cost incurred by a couple undergoing in vitro fertilization and embryo transfer is in the range of R8000 to R12000 per treatment cycle. Patients need to meet this expenditure before the commencement of their treatment cycle. In case the treatment cycle is unsuccessful couples may undergo further cycles which require more OPP. In comparison, an international survey of 25 low-

resource countries documented 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).

1.3 The Impact of Out-of-pocket Expenditure on Households

It follows, that disease and ill-health not only cause suffering and death but also have important financial cost. It is now thought that health services not only have a responsibility in preventing morbidity and mortality but to insure that health systems aim at financial protection thereby reducing the impact of health care costs on poor people.

The absence of financial protection against health- related costs through a system of prepayment and risk pooling, which forms the basis of both health insurance and health tax funding, is a major short coming of many health systems, especially in middle and lower- income countries. Out-of-pocket payments are considered the most ineffective and inequitable means of financing health care (Knaul et al, 2008). Several publications have documented the high rates of catastrophic and impoverishing health costs incurred through OPP in various countries, and the problem is receiving international recognition (Knaul et al, 2008).

A health expenditure that threatens a household's ability to maintain its subsistence needs is termed as catastrophic. It does not necessarily equate to a high health-cost as even small expenditures can financially devastate poor households. Catastrophic health care expenditure implies that a household has to reduce basic expenditure over time in order to cope with health care costs, yet there is no agreement in the literature regarding what threshold proportion of household expenditure represents catastrophic expenditure (Xu et al 2003). Past studies have defined these thresholds as 10% to 40% of a household's capacity to pay after meeting basic subsistence requirements which are mostly related to food (Xu et al, 2003; Knaul et al, 2006). A household's capacity to pay is defined as effective income remaining after basic needs are met. Effective income is taken to be the total consumption expenditure of the household, which in many countries is a more accurate reflection of purchasing power than income reported in household surveys (Xu et al, 2003). Impoverishing health expenditure is defined as a cost that pushes a household below the poverty line or which deepens the existing level of poverty of a household (Knaul et al, 2006).

Little is known about what characteristics protect households from catastrophic payments or the factors that contribute to it. A review of the available literature gives insight into various aspects associated with catastrophic health care expenditure.

A few studies have shown that socio-economic status of the household is a key determinant of catastrophic health care expenditure. Poverty and ill health are linked. Poor countries tend to have worse health outcomes than richer countries. Within poor countries, poorer groups of people have worse health outcomes than better-off people. This relationship shows causality running in both directions: poverty breeds ill health and ill health keeps people poor (Wagstaff, 2002). Poor households can have difficulty accessing health care and when they seek care, they spend a greater proportion of their income on treatment which can be catastrophic compared to wealthier groups. Moreover, it has been documented that poor people may have to pay higher fees to providers, and have higher interest rates on their debts. This is due to poor people's lack of assets to act as collateral to loans or their lack of lucrative social connections to access more funds. In contrast, the wealthier people have a higher probability of obtaining care when sick, are more likely to be seen by a doctor and have a higher chance of receiving medications than the poorer groups (Makinen et al 2000).

The Burkina Faso study showed that poor socio-economic status, large household size, the type of health care facility used (private or public), frequent illness episodes as well as a household headed by an elderly person were important factors in leading to catastrophic health expenditure (Su et al 2006, Russell 2006).

The EQUITRAP project (2005), which looked at catastrophic health care expenditure in Asia, concurred with these observations. It added that rural location, old age, female gender and poor living conditions were all associated with catastrophic health expenditure, while an educated household, an employed head of the household and health insurance were all protective factors.

Chronic illness is a key factor in developing catastrophic health care or impoverishing expenditure (Knaul et al, 2006). This has been supported by McIntryre et al (2007) who showed that cost burdens are related to disease type. Chronic conditions such as HIV and tuberculosis impose higher total costs on households than acute illnesses such as malaria.

1.4 Out-of-pocket Payments and Coping Strategies

Coping strategies are actions that members of households adopt in order to help the household maintain its livelihood and successfully overcome their economic 'shocks'. The concept of coping strategies was initially described in response to famines in Africa in the mid 1980s by Amartya Sen. Sen (1981) described how responses to crises depended on household commodities. These household resources are central to the ability to pay and the different potential strategies available to a household to overcome such crises. Sen also drew attention to the potential danger for a household in sacrificing an investment or lucrative asset. The first study that specifically looked at households strategies to cope with illness was conducted by Sauerborn et al (1996) in Burkina Faso. The following coping strategies were described: using cash and mobilising savings, deferring expenditure (i.e. education), sale of assets, loans, income diversification, gifts, mutual support and reducing on food. Sauerborn (1996) also described a coping strategy of ignoring illness and hence trying to avoid health-related costs altogether. Longhurst and Moser (1998) described three categories of coping, namely production, social and expenditure. In the production category, we see diversification of income, domestic mutual support, minimisation of current commitments to others and sale or mortgage of assets. In the social category, households break social ties and reduce social interaction. When it comes to expenditure adjustments, Moser (1998) described cutting back on total spending followed by a change in dietary habits along with cut backs on purchasing non-essential items. When costs have been incurred for ill health, households may use more than one coping strategy in order to protect the livelihood of the household. Subsequently research has documented that there are similar responses to the costs of ill health across different countries and types of illness. What coping strategies households adopt are, however, dependent on the household's economic, social and cultural features (EQUINET Study, 2000).

1.5 Present Study

To the best of our knowledge there has not been a study looking at how infertile couples finance IVF treatment in developing countries. This study was born out of the need to understand how households, that are inflicted with infertility, cover the cost of IVF treatment, how ART influences household behaviour, resource allocation decisions and to what extent increasing health care expenditure impacts on household budgets and livelihood.

It was the aim of this study to expose the impact of out-of –pocket payments for ART treatment within the public health sector on the economy of households. Specifically,

we wanted to assess the magnitude of out-of-pocket expenditure for ART and the prevalence of catastrophic health care expenditure. The secondary aims were to assess coping strategies, the opportunity costs and to what extent the financial burden of treatment contributes to the experience of ART-related psychological stress.

2. Methods and Participants

2.1 Research Design

The ART cost study has been conducted as a prospective quantitative descriptive study.

2.2 Research setting

The ART cost study was carried out at the IVF clinic of the Reproductive Medicine Unit, Groote Schuur Hospital and Faculty of Health Sciences, University of Cape Town. As described before, this clinic is the only clinic in South Africa to offer tertiary level infertility care within the public sector. Every year approximately 500 new couples are referred to this clinic from the greater Western Cape seeking infertility treatment. These patients undergo a clinical evaluation and examination and depending on the cause of infertility, treatment is started. Treatment options include fertility enhancing surgery, ovulation induction, artificial insemination and ART. ART is the first line treatment for tubal pathology as well as severe male factor infertility, moderate to severe endometriosis and poor ovarian reserve. ART is the second line treatment when non-ART interventions have not been successful.

Although subsidised by the hospital, ART is, however, not free. Patients have to contribute to the cost of their treatment by buying their infertility drugs as due to budgetary constraints, these are not on hospital code. The average cost incurred by a couple undergoing in vitro fertilization and embryo transfer is in the range of R8000 to R12000 per treatment cycle. Patients need to meet this expenditure before the commencement of their treatment cycle.

Approximately 120 ART cycles are performed in this clinic annually. An extra 30 cycles are carried out by contributing private doctors who use the clinics laboratory facilities to treat private patients. Owing to these patients' different financial means, they were excluded from the study.

The patient recruitment was conducted between November 2008 and June 2010.

2.3 Definition of Terms

Index Cycle: This refers to the first ART cycle that couples underwent once recruited to the study

Previous ART cycle at a facility other then GSH: this refers to the couples ART history of prior ART treatment which occurred outside of the study time frame. These cycles of ART were performed at facilities mostly in the private sector.

Previous ART cycle at GSH: this refers to the couples' previous ART history at GSH but which occurred before the study period.

Repeat Cycles: refers to a small group of patients that had another cycle of ART over and above the index cycle which occurred in the study time frame.

Indirect Costs: refer to all the costs related to lost time and productivity.

Direct cost per ART: total money paid to hospital for one ART cycle plus the cost of transport.

Annual household non-food expenditure: monthly non-food expenditure times by twelve months of the year

Monthly Household non-food expenditure: total money paid by household for all expenses except food

Catastrophic costs were calculated at a 40% and 20% threshold by annual direct cost of ART divided by annual non-food expenditure for the 40% and 20% threshold respectively.

2.4 Study Participants and Recruitment

2.4.1 Study Participants

At the initiation of an ART cycle, patients were informed of the study. All couples undergoing ART were asked to participate in the study. Both partners were invited to participate but if one partner was unwilling or unable then the other partner could enter the study alone.

2.4.2 Inclusion Criteria and Exclusion Criteria

All couples undergoing ART at the infertility clinic of Groote Schuur Hospital during the recruitment period were included in the study.

Patients who were unable to converse in Xhosa, Afrikaans or English were eligible to participate in the study.

Those patients, who were under private practitioners undergoing a private cycle at the infertility clinic, were excluded as they did not fall into the public sector of patients. Patient who also had non-ART treatments initially but then got converted to an IVF cycle were also excluded from the study.

2.4.3 Recruitment

Actual recruitment occurred after an ART cycle had been completed. Patients were invoiced by the hospital no later than three weeks following the date of egg retrieval. This invoice captured all the procedure related costs and cost of the blood tests owed to the hospital. The couples had to pay for their infertility drugs required for ovarian stimulation at the beginning of the ART cycle.

Once a couple had been started on an ART cycle, they were contacted telephonically by a researcher using their contact information from the folder. A date for the interview was scheduled, between weeks 3-6 after egg collection .This enabled the researcher to assess the full impact of the OPP for that cycle. Couples knew the outcome of the cycle, whether it was successful or not as pregnancy tests were done on about day 14 after embryo transfer. The researcher invited the participants to an interview. At the interview the study and its objectives were explained and written informed consent was obtained from the participants. The interview was then held and data recorded. If the interview did not coincide with the couples follow up appointments, it was made when convenient to the patients and the researcher. If this occurred, transport money was reimbursed.

As the implications of the OPP could be expected to change in subsequent cycles, couples could enter the study more than once if they were undergoing more than one cycle in the study period. Couples were recruited until the numbers of planned interviews were completed.

Please see Appendix 2 which outlines the clinical aspects of an ART cycle.

2.4.4 Sample Size

A total of 85 ART cycles were surveyed. This sample size was derived on empirical grounds as there are no pre-existing data on which to base the sample size. It was anticipated that the sample size would provide relevant insights into the research questions.

2.5 Study Instrument

A six part questionnaire was developed by the Infertility Department at Groote Schuur in collaboration with the Health Economics Department at UCT. (See Appendix1).

The questionnaire was developed using standard questions that have been used previously in national household surveys conducted by STATSA (the national statistical authority) and the SACBIA (South African Consortium for Benefit Incidence Analysis). The latter survey was a collaborative initiative by the Health Economics Unit, University of Cape Town; Centre for Health Policy; University of the Witwatersrand; The National Department of Health and the London School of Hygiene and Tropical Medicine.

The Questions used are therefore not new and have been validated. They satisfy face, content and context validity. No new questions were generated which needed to be newly tested in this study.

Despite using established questions, the questionnaire was piloted on five couples. This further validated the questionnaire for our particular study. The pilot study revealed that the order of the questionnaire needed to be changed in order to improve responses to certain questions.

Part A of the questionnaire captured background information of the couple receiving ART treatment which included basic socio-demographic details.

Part B captured information on the nature of the couple's relationship and the number of existing children.

Part C focused on costs and coping strategies of previous ART at facilities other than Groote Schuur Hospital.

Part D focused on information of costs, OPP and coping strategies for previous ART treatment at Groote Schuur Hospital.

Part E looked at information around the cause of the couples' infertility, costs, OPP and coping strategies for the index cycle. When couples have undergone previous ART at Groote Schuur Hospital, reported information on OPP was compared with the information available within the patient's folder. This part of the questionnaire also examined the financial impact that ART had had on couples' households while undergoing ART treatment by means of Likert type scale questions as well as an

open ended question. It also focused on the amount of stress ART had caused the participants and to what proportion OPP accounted for overall stress.

Part F captured household socio-economic information that helped create a composite household score.

2.6 Data Collection

The questionnaires were processed by the primary researcher, Kerry Sherwood, who was not involved with the infertility service. An English version of the questionnaire was translated into Xhosa and Afrikaans. To ensure accurate translation, the questionnaires were also back translated by an independent translator. Couples who were fluent in English had their interviews conducted in English. Afrikaans and Xhosa versions were used when English was not the patient's first language. In addition to the primary researcher conducting interviews, a research assistant helped with data collection. The research assistant was fluent in English, Afrikaans and Xhosa. These interviews were checked by the primary researcher.

The interviews were conducted where ever suitable for the patients. This was mostly carried out in a quiet room in the IVF clinic, yet if it was convenient, the interviews were held at patient private residences or places of employment. Emphasis was placed on conducting the interviews in a caring, empathetic manner. The researchers also outlined the importance of gaining truthful answers as far as possible yet maintaining confidentiality of all information.

A single questionnaire was used irrespective of whether one or both partners participated in the interview. If both partners participated, then only consensus answers were recorded. In the case of non-consensus, couples were asked to reach an agreement and the agreed upon answer was recorded.

2.7 Data Processing

All completed questionnaires were entered into an electronic data base. A second data base was created to capture the direct and indirect cost of the ART cycles, as well as the total household expenditure minus food expenditure. This data base also included a time line of the patients ART treatments within twelve months of the index cycle.

2.8 Data Analysis

Demographic data, coping strategies and ART treatment- related direct and indirect cost on households were evaluated by descriptive analysis.

Three dependent variables were identified: catastrophic cost, coping strategies, and emotional and financial stress. These were cross analysed against other variables in order to establish relationships and associations. Catastrophic cost was further analysed in relationship to other questions on the financial impact of ART on households (i.e. question 30 of the questionnaire, Appendix 1). Statistical significance was determined by the Pearson Chi squared test where significance was determined if the P-value was less or equal to 0.05.

Using the second data base, total costs of ART were compared to estimates of non-food household expenditure, to determine the cost burden level for each household and to determine to what extent it may be catastrophic i.e. catastrophic health care expenditure is equal to total health cost divided by total non-food household expenditure. We calculated the prevalence of catastrophic expenditure among the households and two threshold/cut-off levels of 20% and 40% of non-food expenditure were used.

The Likert scales, capturing stress related to ART treatment, were scored and ranked and the variations in the scores assessed.

The data derived from the open-ended question was evaluated by breaking the data up into categories containing themes or concepts. For the presentation of the findings, operationally defined verbal counting was used (Sandelowski, 2001). Operationally defined verbal counting defines words such as a “few”, “some” and “many” as well as “majority” and “several”. In this study a “few” refers to more than one patient or household but less than seven. The words “some” or “several” refer to households or groups of patients of 8 to 15, with “some” referring to the lower numbers and “several “to the upper limits of this range. If a result was between 16-25 patient groups or households then the term “many” was applied. The word “most” was used to describe 30 to 40 household or patients while “majority” was used for numbers over 40 for a particular theme.

A principle component analysis was planned to develop a composite index of socio-economic status of the households. This score would be used to compare our study population to the greater Western Cape population as well as identify which socio-economic category each couple fell into, thereby allowing comparisons to be made

across socio-economic groups. Unfortunately this analysis was not able to be done at this point in time as the Western Cape community surveys data base was inadequate to determine this proposed analysis. Hence, tertiles of socio-economic status were formed which categorized the households into poorest to least poor. The frequency of catastrophic health care cost was determined for each tertile.

2.9 Ethics

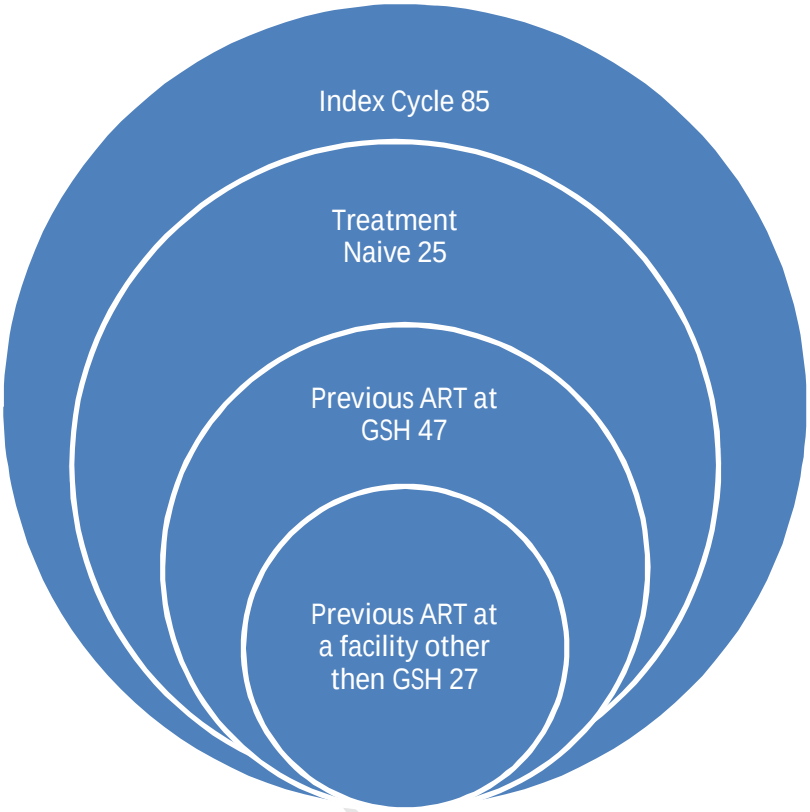
The study was approved by the Research and Ethics Committee of the University of Cape Town. All participants had the aim and the objective of the study explained to them at the beginning of the interview and written consent to participate in the study was obtained. Patients were also reminded that declining to participate in the study did not jeopardize their current or future treatment. All participants were informed that the data collected would remain confidential.

3. Results

A total of 105 couples were eligible to participate in the study. Twelve patients refused on the grounds of not having time for an interview or not being interested. Twelve people were from out of town and had returned home before being able to interview them and seven patients were not contactable, thus leaving 75 couples interviewed. Ten couples had had repeat cycles of IVF treatment since the commencement of the study which resulted in 85 index cycles being analysed.

In those 85 cycles there were couples who had undergone previous ART treatment, while the remainder were treatment naive. Of the latter, 27 couples had had ART in facilities other then Groote Schuur Infertility Clinic and this was mainly in the private sector, while 47 couples had had previous ART treatment at Groote Schuur Infertility clinic before the onset of the study. There were also 10 couples who had a repeat cycle subsequent to the index cycle within the study period; these are referred to as repeat cycles.

Figure 1: Types of ART Treatment



3.1 Demographic Information

The socio-demographic characteristics of the participants are listed in Table 1 and Table 2.The repeat cycle variables were excluded for the socio-demographic data as these variables did not change between the index cycle and repeat cycle for the study time frame. The majority of couples were Coloured followed by Black Africans with the minority being Europeans and Asian/Indians. Most of the couples were married, either by South African law or through religious and cultural traditions. The average age for male participants was 39.1 years and 35.1 years for female patients. The majority of couples had completed secondary school. In terms of higher education, more women had obtained a diploma or degree compared with the men.

TABLE 1: Table of Socio-demographic Information of the Study Population.

SOCIODEMOGRAPHIC INFORMATION N=75 couples	**N**	**%**	**95% confidence interval**
Ethnic Group			
Coloured	30	40.00	[28.65% 51.35%]
Black	26	34.67	[23.64% 45.69%]
White	12	16.00	[7.51% 24.49%]
Asian/Indian	7	9.33	[2.60% 16.07%]
Marital Status			
Married	65	88.67	[78.79% 94.54%]
Traditional/Islamic	3	4.00	[-0.54% 8.54%]
Living with partner	5	6.67	[0.89% 12.44%]
Single (never married)	1	1.33	[-1.32% 3.99%]
Separated	1	1.33	[-1.32% 3.99%]
Medical Aid Member			
One Partner	5	6.66	[0.89% 12.44%]
Both Partners	38	50.66	[39.09% 62.25%]
None	32	42.66	[31.21% 54.12%]

TABLE 2: Socio-demographic Information of the Study Population

SOCIO-DEMOGRAPHIC INORMATION N=75 couples	WOMEN			MEN		
	N	%	95% CI	N	%	95% CI
Education						
Primary Education (1-7 years of schooling)	3	4.00	[-0.54% 8.54%]	11	12.68	[6.47% 22.86%]
Secondary Education (8-12 years of schooling)	40	53.33	[41.78% 64.89%]	38	52.11	[40.20% 64.02%]
Completed Tertiary Education (Degree or Diploma)	32	42.67	[31.21% 54.12%]	26	35.21	[23.83% 46.60%]
Employment Status						
Full time employed	44	58.67	[47.26% 70.07%]	50	70.42	[59.54% 81.30%]
Part time/Contract	1	1.33	[-1.32% 3.99%]	3	4.23	[-0.57%9.02%]
Self employed	11	14.67	[6.47% 22.86%]	14	19.72	[10.23% 29.20%]
Casual	4	5.33	[0.13% 10.54%]	4	5.33	[0.13% 10.54%]
Unemployed/Housewife/Student	15	20.00	[10.73% 29.27%]	4	5.33	[0.13% 10.54%]
Age (Years)						
Mean	35.1			39.1		
Range	22-46			28-55		
95% CI	[33.89 36.27]			[37.72 40.51]		

3.2 Socio-economic Information

The socio-economic characteristics are listed in Table 3. For these characteristics we included the repeat cycle variables making 85 cycles analysed as some of these variable could have changed between index and repeat cycles for the study time frame. The average household size was 3.34 with a range of 1 to 8 people. The mean monthly household expenditure was calculated at R11, 872.71 with a wide range (R1, 390.83 to R 75,133.34). The median monthly household expenditure was R8, 782.91.

Most of the couples were in full time employment. More women were unemployed compared with the male participants. The majority of couples belonged to a medical aid scheme.

The majority of households were equipped with basic amenities. All the households had electricity, water and flush toilets that were either connected to sewage or septic tanks. Nearly all the households had a fridge and a cell phone. Only 43 households had access to a Telkom telephone lines while 68 households owned a car.

Over 85 percent of the households lived in formal housing whether the houses existed on separate pieces of property, were town houses, a semi-detached house or a flat. Sixteen percent of the households lived in informal housing ranging from a room in an existing dwelling, to a room in a back yard or a shack.

TABLE 3: Socio-economic Information of the Study Population

SOCIO-ECONOMIC INFORMATION **Number of Households surveyed N=85**	**MEAN**	**RANGE**	**95% confidence interval**
Household Size(Std Dev)	3.34(1.84)	(1-8)	[2.942 3.740]
Monthly Household Expenditure (Median)	R11 872.71(R8 782.92)	(R1 390.83-R75 133.34)	[9403.984 14341.43]
Basic Amenities of Households	**N**	**%**	
Running Water in dwelling	79	92.94	[87.38% 98.50%]
Electricity	85	100	[-]
Flush Toilet (connected to sewage)	73	85.88	[78.33% 93.44%]
Telkom Phone	43	50.59	[39.74% 61.44%]
Cell Phone	85	100	[-]
Fridge	83	97.65	[94.36% 100.94%]
Computer	49	57.65	[46.93% 68.37%]
Internet	24	28.24	[18.47% 38.00%]
Car	68	80.0	[71.32% 88.68%]
Type of Household			
Formal house on separate land	51	60.71	[50.05% 71.38%]
Town House/Cluster/Semi-detached	12	14.29	[6.65% 21.93%]
Flat	8	9.52	[3.12% 15.93%]
Room in a dwelling	3	3.57	[-0.48% 7.62%]
Room in a backyard	5	5.96	[0.79% 11.12%]
Shack	3	3.57	[-0.48% 7.62%]
RDP housing	3	3.57	[-0.48% 7.62%]

3.3 History of Infertility:

The infertility characteristics are summarised in Table 4. With regard to the infertility variables, we excluded the repeat cycles because the cause of infertility, number of existing children and years of infertility did not change between the index cycle and the repeat cycle. The commonest cause of infertility was tubal factor and male factor, which together accounted for more than two thirds of cases. Most couples had experienced long relationships with their partners and had lived through many years of infertility. The majority of couples were childless in union. Only eight couples had a child in their current relationship. Men were more likely to have had children from previous relationships when compared with women.

TABLE 4: Infertility Information on the Study Population

INFERTILITY INORMATION **N=75 couples**	**N**	**%**	**95% Confidence interval**
Indications for ART			
Tubal Factor	32	37.64	
Male Factor	31	36.47	
Anovulation	12	14.11	
Age-related Infertility	11	12.94	
Endometriosis	8	9.41	
Unexplained Infertility	8	9.41	
Other	13	15.28	
Children in Union			
Yes	8	10.67	[3.52% 17.82%]
No	67	89.33	[82.18% 96.48%]
Children from Previous Relationships			
Women			
Yes	10	13.33	[5.46% 21.21%]
No	65	86.67	[78.79% 94.54%]
Men			
Yes	30	40.00	[28.65% 51.35%]
No	45	60.00	[48.65% 71.35%]
Duration of:	MEAN	STD DEV	95% CI
Infertility Years (Range)	6.4 (0.5-17)	3.45	[5.586 7.174]
Relationship Years (Range)	9.7 (1-30)	4.65	[8.584 10.722]

3.4 Financial Impact of the Index Cycle

Eighty-five index cycles were analysed. Direct costs refer to all financial payments made in seeking and obtaining health care. The direct cost for ART treatment also includes transport costs. The mean direct cost for an Index cycle was R11 527.29 (R2 900 to R20 750) with a median cost of R11 500. The average transport costs for the couples were R137.72 (R0 –R5470).The mean indirect cost for the index cycle was R612.80 (See table 5).

The catastrophic costs for the index cycle were determined at different thresholds. At the 40% threshold, 35.5% of households experienced catastrophic health care expenditure. A higher rate of catastrophic expenditure was seen at lower cut-off point. For example over two thirds of the households' experienced catastrophic costs at a 20% threshold (see Figure 2.)

Tertiles of socio-economic categories were created and based on per capita household expenditure. The categories were divided into poorest, middle and richest household tertile. Sixty-six percent of households in the poorest tertile made catastrophic health care expenditure compared to seven percent of households in the richest tertile.

The coping strategies for the index cycle included: reducing on household spending, accessing savings, selling assets, borrowing money, receiving financial gifts as well as taking on extra work (See Figure 3 and Table 6).

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 in the index cycle. Children's education, paying for existing children as well as completing renovations on the family home were areas were couples decreased on payments in order to redirect money to ART treatment (See Figure 4 and Table 6).

Lastly, there were 38 households in which a member of the family took on extra work in order to generate extra income for ART.

The participating couples were asked through closed questions how often the household had struggled to pay bills, pay for household basics, or for other medical episodes in the past year. According to the results, 40% of households struggled to pay their bills, 37% could not afford household basics and 32 % could not pay for their health care needs other than IVF (See Table 7).

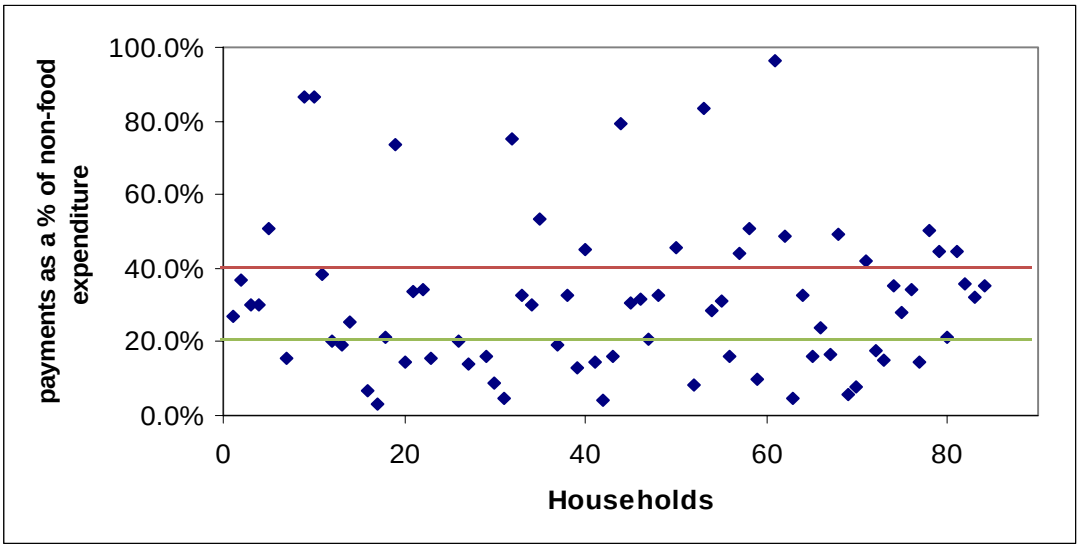
By means of a five point Likert-scale question, the informants were asked to describe the financial impact that ART treatment has had on their households. In this self assessment of impact, over half the households assessed that their households were coping but with difficulty, while nearly 5 % of the households felt that the survival of the household was threatened (See Table 7).

Finally, emotional and financial stress were analysed using a five point Likert- scale question. The majority of both men and women demonstrated a high level of both emotional and financial stress. There were slight gender differences. Women felt more emotionally than financially stressed in the extremely stressed category whereas men felt more financially stressed for the same category. This difference was, however, not statistically significant (See Table 8).

TABLE 5: Financial Impact of the Index Cycle

INDEX CYCLE N=85 Cycles			**95% confidence interval**
Direct Cost			
Mean (Std Dev)	R11 527.29 (R3599.07)		
Range	R2 900-R20 750		[10735.12 12319.47]
Indirect Cost			
Mean	R612.80		[453.88 771.72]
Amount Borrowed			
Mean (Std Dev)	R8 136.36 (R7170.83)		[6197.82 10074.91]
Range	R0 - R30 000		
Transport Cost			
Mean (Std Dev)	R137.72 (R590.25)		[9.69 265.75]
Median	R50.00		
Range	R0-R5470		
Catastrophic Cost (annual non-food expenditure) Threshold	**N**	**%**	
10%	75	88.2	[81.24% 95.23%]
20%	**59**	**69.4**	[59.41% 79.41%]
30%	47	55.3	[44.51% 66.08%]
35%	35	41.2	[30.50% 51.85%]
40%	**30**	**35.3**	[24.93% 45.66%]
45%	26	30.6	[20.59% 40.59%]
Tertile of Socio-economic status that made catastrophic payment			
Poorest	29	66	[47.12% 83.92%]
Middle	28	32	[13.70% 50.58%]
Richest	28	7	[-3.03% 17.31%]
Repeat Cycles (N=10) that made catastrophic payment			
Poorest	3	67	[-76.76% 210.09%]
Middle	4	50	[-41.87% 141.87%]
Richest	3	0	[-]

Figure 2: Scatter Graph Showing the Distribution of Catastrophic Costs



3.5 Repeat Cycles

There were ten repeat cycles in the study period. The households that had undergone a repeat cycle were categorized into socio-economic tertiles and the catastrophic expenditure was worked out for each household at the 40% threshold. Three households were in the poorest socio-economic category and had a rate of 67% catastrophic health care payments while four households in the middle tertile incurred 50% catastrophic health care costs and three households in the richest tertile had no catastrophic payments. Comparing the first index cycle with the repeat cycles for these ten households, four couples admitted that they were more emotionally stressed and six couples more financially stressed by the subsequent cycle than when undergoing the index cycle. In the self assessment question on the impact of ART on the household, four households assessed their households on a higher score in the subsequent cycle while the other six households remained unchanged. Changes in the households' ability to meet their financial obligations in the subsequent cycle were noted. Four of the ten households admitted to struggling to pay bills, five households said they could not afford household basics while two of the households stated they could not afford to pay for other medical events. Analysis of the coping strategies adopted in the index cycle and the repeat cycle found that three households had used an additional coping strategy in the repeat cycle. These additional coping strategies ranged from taking on extra work, reducing rent, reducing on education and reducing on existing child support. The remaining households did not adopt a different coping strategy in the subsequent cycle.

TABLE 6: Financial Coping Strategies for the Index Cycle

Financial Cost Coping Strategies For Index Cycle N=85 Cycles	N	%	95% confidence interval
Savings			
Savings Accessed	53	62.35	[51.84% 72.87%]
All Savings Utilised	60	76.92	[60.70% 80.47%]
Number of Households that Borrow Money	41	48.24	[37.39% 59.08%]
Access to loans	24	28.24	[18.47% 38.00%]
Bank Loans	17	20.00	[11.32% 28.68%]
Informal Loans	30	35.29	[24.93% 45.66%]
Interest on Loans	34	40.00	[29.37% 50.63%]
Existing Debt /Outstanding Loans			
Number of Households that reduced spending	77	90.59	[84.25% 96.92%]
Reduction of Household expenditure on:			
Clothing	78	91.79	[85.80% 97.73%]
Food	75	88.25	[81.24% 95.23%]
Entertainment	69	81.18	[72.69% 89.66%]
Education	15	17.65	[9.38% 25.92%]
Rent	11	12.94	[5.66% 20.22%]
Water and Electricity	7	8.23	[2.27% 14.20%]
Existing Children	4	4.70	[0.11% 9.30%]
Financial Gift	13	15.31	[7.48% 23.10%]
Sold Asset	10	11.76	[4.77% 18.76%]
Extra Work	38	44.71	[33.92% 55.49%]
Medical Aid Reimbursement	5	5.88	[0.78% 10.99%]

Figure 3: Percentage of Households: Financing ART

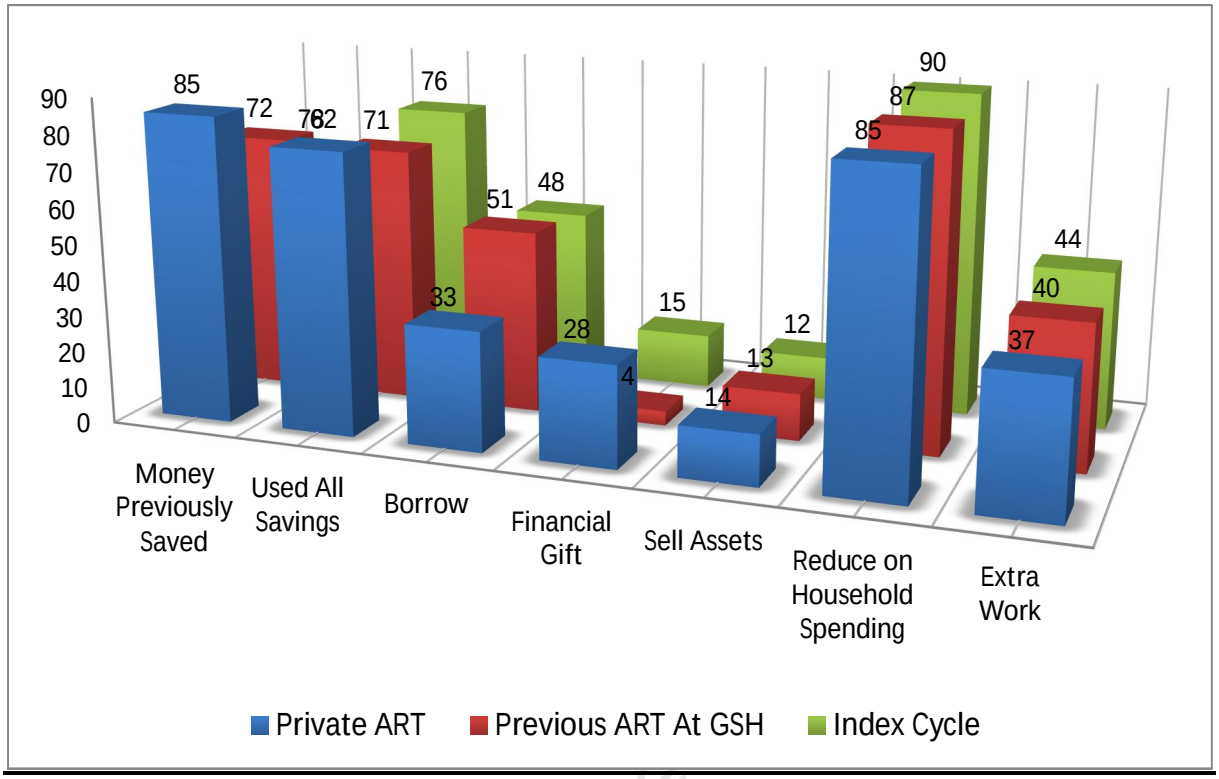


Figure 4: Reductions on Household Expenses.

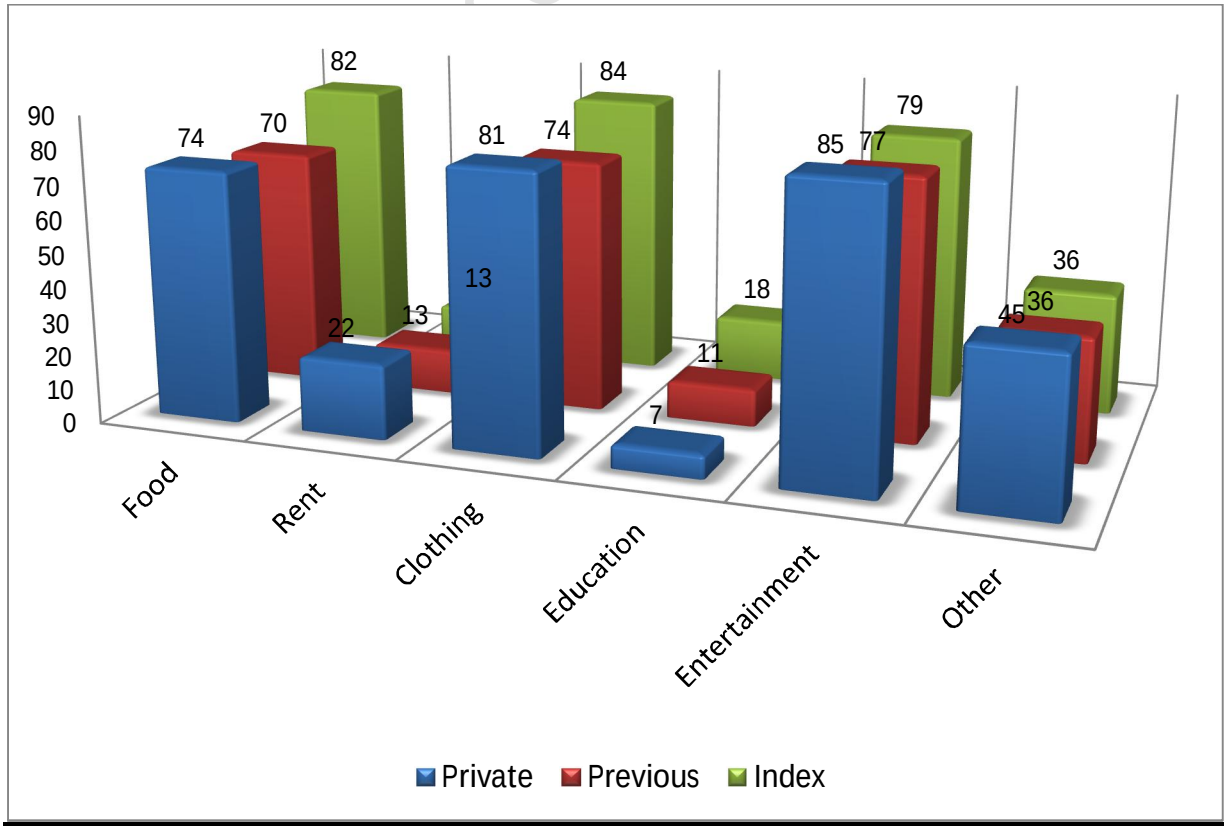


TABLE 7: Financial Impact of ART

Assessment of ART Impact On Households N= 85 Cycles	N	%	95% confidence interval
Struggling to Pay:			
Bills			
Never	26	30.59	[20.59% 40.59%]
Not very Often	25	29.41	[19.53% 39.30%]
Fairly Often	22	25.88	[16.38% 35.39%]
Very Often	12	14.12	[6.56% 21.67%]
Household Basics			
Never	29	34.12	[23.83% 44.40%]
Not very Often	24	28.24	[18.47% 38.00%]
Fairly Often	23	27.06	[17.42% 36.70%]
Very Often	9	10.59	[3.91% 17.26%]
Health Care			
Never	45	53.57	[42.11% 63.77%]
Not very Often	12	14.29	[6.56% 21.67%]
Fairly Often	15	17.86	[9.38% 25.92%]
Very Often	12	14.29	[6.56% 21.67%]
Financial Impact of ART			
Minimal	4	4.76	[0.11% 9.30%]
Manages Easily	8	9.52	[3.08% 15.75%]
Copes but with difficulty	49	58.33	[46.93% 68.37%]
Still recovering	19	22.62	[13.31% 31.39%]
Survival is Threatened	4	4.76	[0.11% 9.30%]
Lost Income through taking time off **Work to have ART**	35	41.18	[30.50% 51.85%]

TABLE 8: Emotional and Financial Stress

Degree of Stress N=85 Cycles	Female N	Male N
Emotional Stress		
Not Stressful	0	1
A little bit stressful	12	8
Moderately stressful	17	22
Quite a bit stressful	14	19
Extremely Stressful	42	35
Financial Stress		
Not Stressful	2	0
A little bit stressful	11	13
Moderately stressful	18	17
Quite a bit stressful	27	26
Extremely Stressful	27	29

3.6 Information on Previous ART at Groote Schuur Hospital

Forty-seven couples had had previous cycles at the Infertility Clinic at Groote Schuur Hospital which were not included in this study. The cost of this previous treatment and the coping strategies used are shown in Tables 9 and 10.

TABLE 9: Financial Impact of Previous ART at Groote Schuur Hospital

Previous ART at GSH N=47 Cycles	**N**	%	**95% confidence interval**
Total Number of Previous Cycles	47	55.29	[44.51% 66.08%]
Medical Aid Reimbursement	5	10.64	[1.49% 19.79%]
Direct Cost Mean (STD DEV) Median Range	R18 523.06 (R18 620.03) R13 000.00 R4 000-R120 000		[12959.82 24086.31]
Indirect Cost Mean	R 2691.49		[687.14 4695.84]
Amount Borrowed Mean(STD DEV) Range	R13 163.33 (R 11 789.69) R0 – R40 000		[8760.989 17565.68]
Transport Cost Mean(STD DEV) Median Range	R 1044.63 (R 2 352.40) R500.00 RO-R15 000		[292.94 1796.33]
Number Of Cycles Mean Range	2 1 – 10		[1.46 2.41]

TABLE 10: Financial Coping Strategies Adopted in Previous ART Cycles at Groote Schuur Hospital

Direct Cost Coping Strategies of The Previous ART At GSH N=47 Cycles	N	%	95% confidence interval
Savings			
Savings Accessed	34	72.34	[59.06% 85.62%]
All Savings Utilised	29	70.73	[56.19% 85.27%]
Borrow Money	24	51.06	[36.23% 65.90%]
Access Loans			
Bank Loans	15	31.91	[18.08% 45.75%]
Informal Loans	9	18.15	[7.47% 30.83%]
Interest on Loans	19	40.43	[25.86% 54.99%]
Existing Debt /Outstanding Loans	18	38.30	[23.87% 52.73%]
Number of HH that Reduced Spending	41	87.23	[77.33% 97.14%]
Reduced expenditure on:			
Clothing	39	82.97	[71.82% 94.13%]
Entertainment	37	78.72	[66.58% 90.87%]
Food	35	74.46	[61.53% 87.41%]
Rent	6	12.77	[2.86% 22.67%]
Education	5	10.64	[1.49% 19.79%]
Existing Children	3	6.38	[-0.87% 13.64%]
Petrol	2	4.26	[-1.74% 10.25%]
Financial Gift	2	4.26	[-1.74% 10.25%]
Sold Asset	6	12.77	[2.86% 22.67%]
Extra Work	19	40.43	[25.86% 54.99%]

HH= Household

3.7 Information on Previous ART at a Facility other than Groote Schuur Hospital

Twenty-seven couples had received ART in institutions other than Groote Schuur Hospital. The majority of these were in private clinics. The mean number of cycles that the couples underwent was 2.1.The average financial burden (direct cost plus indirect costs) per cycle was R28 766.30.The revealed costs and coping strategies are captured in Table 11 and 12.

The majority of couples stopped treatment at their previous facilities as they could no longer afford the treatment offered. Six couples moved to Groote Schuur for perceived better quality of care while four couples had been referred by their primary physician.

TABLE 11: Financial Impact of ART in Previous Cycles at Institutions other than Groote Schuur Hospital

Previous ART at A Facility Other Then GSH N=27 Cycles	**N**	**%**	**95% confidence interval**
Total Number of Previous Cycles	27	31.76	[21.66% 41.87%]
Medical Aid Reimbursement	3	11.11	[-1.56% 23.78%]
Direct Cost			
Mean(STD DEV)	R26 738.89 (R20 165.87)		[18761.54 34716.24]
Median	R25 000.00		
Range	R2000-R77 000		
Indirect Cost			
Mean	R2027.41		[443.96 3610.85]
Amount Borrowed			
Mean(STD DEV)	R11 866.67		[4148.08 19585.25]
Std Dev	13 937.96		
Range	R0 – R35 000		
Transport Cost			
Mean (STD DEV)	R650.00 (R595.89)		[392.32 907.68]
Median	R500.00		
Range	R0-R2000		
Number Of Cycles			
Mean	2.31		[1.47 3.17]
Range	1 – 9		

TABLE 12: Financial Coping Strategies Adopted in Previous ART Cycles at Institutions other than Groote Schuur Hospital

Direct Cost Coping Strategies of Previous ART At a facility Other Then GSH N=27 Cycles	**N**	**%**	**95% confidence interval**
Savings			
Savings Accessed	23	85.19	[70.86% 99.51%]
All Savings Utilised	21	77.78	[61.02% 94.54%]
Borrow Money	9	33.33	[14.33% 52.34%]
Accessed Loans			
Bank Loans	6	22.22	[5.46% 38.98%]
Informal Loans	3	11.11	[-1.56% 23.78%]
Interest on Loans	9	33.33	[14.33% 52.34%]
Existing Debt Outstanding Loans	3	11.11	[-1.56% 23.78%]
Number of HH that Reduced Spending	23	85.19	[70.86% 99.51%]
Reduced expenditure on:			
Entertainment	26	96.29	[88.68% 103.91%]
Clothing	23	85.18	[70.86% 99.51%]
Food	21	77.77	[61.02% 94.54%]
Rent	7	25.92	[8.26% 43.59%]
Petrol	3	11.11	[-1.56% 23.78%]
Education	2	7.41	[-3.15% 17.96%]
Financial Gift	8	29.62	[11.22% 48.04%]
Sold Asset	4	14.81	[0.49% 29.14%]
Extra Work	10	37.04	[17.57% 56.50%]

HH=Household

3.8 Cross Tabulations: Predictors of Catastrophic Expenditure

In order to find associations or predictors of catastrophic expenditure we cross tabulated three dependent variables namely catastrophic cost, coping strategies and emotional and financial stress against other variables. Statistical significance was determined by the Pearson Chi squared test where significance was if the P-value ≤ 0.05.

Significant predictors of catastrophic expenditure were unemployment, no medical aid cover and a lower level of education (primary or secondary level).

In previous ART cycles there was a significant association between two coping strategies, namely taking on extra work and selling assets and catastrophic expenditure was found in the previous ART cycles. In contrast, no significant association between catastrophic costs and these coping strategies were found in the index cycle.

Catastrophic expenditure was significantly associated with emotional stress in women yet no such association was found in men. With regard to financial stress and catastrophic payments there was no statistical significance, however a trend was noticed. High health costs were associated with increasing financial stress.

When analysing the households' self-assessment of financial impact and catastrophic costs, there was no statistical significance. However there was an increased trend showing association between households that had assessed themselves as "coping with difficulty" and "survival is threatened" with higher rates of catastrophic payments.

There was also a significant correlation with certain coping strategies and households perceived higher financial impact scores for the index cycle. Households who adopted coping strategies such as using savings, borrowing money and taking on extra work were significantly more likely to have assessed their households as not coping to potential threatened survival of that household with regards to ART financial impact.

3.9 Results of the Open-ended Question

The questionnaire contained an open ended question where couples could spontaneously share their experiences on how their households had been affected by ART treatment (See question number, appendix 1). This question was not an in-depth interview, but it provided insight into unprovoked thoughts, experiences and feelings of the couples. Following analysis, eleven key themes were identified: financial and emotional stress, opportunity cost and debt, relationships and children, lifestyle and education, coping strategies as well as aspects around future ART treatment and evaluation of the ART process.

3.9.1 Financial stress

The vast majority of households admitted to experiencing financial stress as a result of ART treatment. This financial stress was described in a number of ways. Several informants spoke of their inability to afford basic amenities such as food, electricity and petrol. The following two interview extract shows this concept: “My husband and I now live off R120 per month.” and, “We now make food stretch over two days.” Several couples admitted that they were struggling to make repayments every month. Others said they could not afford to take out another loan in order to keep on financing ART therapy. A few couples confessed that the financial implications of ART had had a negative effect on their relationships causing couples to argue and fight about money. Some participants admitted to “sleepless nights” worrying about money, how they would fund the next cycle and whether the household could really afford to sacrifice further for treatment. Some couples expressed that they felt that the financial stress outweighed the emotional stress of ART process while other couples felt differently. Several couples admitted that ART treatment had brought them to rely on family welfare in order to function. In contrast, few households said that despite ART being expensive their households were coping financially.

3.9.2 Emotional stress

Emotional stress experienced during the IVF processes was experienced by the majority of couples**.** A range of emotions were expressed. A few patients said that the emotional stress was so severe, that they compared it to a trauma or to the bereavement of losing a member of your family. Several couples conveyed a deep desire and longing to be parents. They admitted to saving every last penny to be able to afford IVF treatment which would help them achieve their dreams of becoming parents. Seven of the women in the study confessed to being depressed and seeking medical treatment along with counselling for their depression. One of

the participants even had a breakdown that led to her being admitted into a psychiatric facility in Cape Town. Some patients divulged their disappointment in ART therapy which was centred on unsuccessful cycles. This feeling of disappointment also pertained to finances having run out and that couples would not be able to carry on with fertility treatment.

A few expressed guilt at not being able to provide for their existing children as all available spare income was saved for ART treatment rather than spoiling their existing children. This is shown by this quote by a mother who said: "My daughter is neglected; she is not as spoilt as she should be, and we can no longer afford birthday presents and things that she would like. It is difficult to keep on disappointing her and I feel guilty". Several couples felt "drained" by the ART therapy and expressed that they were emotionally struggling and emotionally 'stuck', unable to accept childlessness and unwilling to accept failure of ART treatment. "Life hangs in the balance", "I feel like I am in limbo" were words used to describe the feeling of being consumed by their infertility, an inability to move forward or cope .A few couples admitted to feeling anxious. These feelings centred on worrying whether a cycle would be successful or not, or worrying about the financial implications of ART treatment, where they would get the next injection of cash to afford treatment, as well as worrying about the sacrifices being made in order to finance treatment.

Anxiety was also expressed in facing childlessness and a few women shared that they continually thought about ART treatment, having a baby and from whence the money for a next cycle would come. Four couples communicated the feeling of intense sadness at not being able to conceive. A few husbands even volunteered that their wives cried all the time from the unfulfilled wish of having a baby. A few admitted to being withdrawn, not able to leave the house and avoiding situations that reminded themselves of their infertility.

Four participants expressed anger, anger at their inability to conceive as well as anger towards their partner. A few patients blamed their partners for causing their infertility as seen by this quote: "I did not talk to my husband for a whole year, I was angry with him as this is his entire fault."A lesbian expressed blame for her desire to conceive as being part of a same–sex relationship there was no other active partner to blame. Anger and blame was also directed at the Government, who were being held responsible for not supplying free health care for infertile couples. This extract is an example of this feeling, "Government can terminate life for free but they can't help create a life." A few Muslim participants conveyed the feeling of pressure, not only to conceive but to have a male child as that was culturally mandatory.

3.9.3 Opportunity costs

The majority of the participants volunteered information on what their households had sacrificed in order to afford ART treatment. One couple described how impoverishing ART treatment can be: "We started not being able to afford luxury things, now we cannot sometimes afford things we really need." Most couples confirmed not being able to afford basic amenities (water/electricity/food/transport money or petrol) to keep their households functioning. The following interview extracts illustrates this concept: "Having been through an ART treatment, we now use candles instead of electricity and we can no longer afford cleaning products." Another stated: "We have no money for transport, we now walk everywhere."Many couples said that if it were not for IVF treatment they would have been able to buy a car. Several participants explained that financing ART treatment had caused them not to be able to do repairs on their houses. Some informants shared that they would have been able to buy their own homes or pay off their existing homes loans if they had not had treatment. Four participants, who owned their own businesses, explained that the money used for ART treatment had prevented them from expanding their businesses as well as causing them considerable loss of income from attending the IVF clinic appointments for treatment. A few households admitted to having no savings, no household insurances or long term investments; these had all been used to finance IVF treatment.

3.9.4 Debt

Most couples mentioned that ART treatment had caused their households to have outstanding debt. Several couples had taken loans from the bank, and some were struggling to meet these loan repayments every month. Undergoing ART treatment had caused several families to be unable to pay bills at the end of the month. A few of these households adopted a system of delayed payment of such bills as a consequence of ART treatment. Some couples used their social networks or families to borrow money from to pay for IVF treatment. Three households admitted to having no money, that they were broke and financially had 'given up'.

3.9.5 Children

Several couples explained the financial impact of ART treatment on their existing children. Six couples felt that they could not provide adequately for their children. They were not able to pay for school fees, school uniforms, text books or other things children need for school, as they had done prior to starting ART treatment. Some couples said that although they were able to still afford school tuition, they

were unable to afford school outings or their children's extracurricular activities. Several families acknowledged that due to ART treatment costs there were no longer surplus funds to spoil their other children. This meant that there were no birthday or Christmas presents, no dinners out or other family outings. A few couples confessed to not being able to afford their children and that other members of the family had taken on financial responsibility for these children. One patient explained that ART treatment had impoverished her so much that even if she did conceive she would not be able to give her child anything.

3.9.6 Relationships

The majority of couples referred to the impact that ART had on their relationships with their partners, extended families as well as their social networks and friends. Several patients mentioned that ART had a negative impact on their relationship with their partner. ART was responsible for strain in marriages. Arguments regarding money for ART were confessed and some women felt unsupported by their partners and families. Two couples had experienced the breakdown of their relationships during the ART process; one was deserted while the other separated from her husband. A few women patients, who were the breadwinners in their families, admitted to feeling extra pressure to keep their household functional and undergo treatment at the same time. They felt that by having to work negatively impacted on their treatment cycles and this had caused tension within their marriages. Only two couples mentioned that they had found the ART process to be a bonding experience.

Several couples also expressed stress within their extended families. Some couples felt that their families had been a financial support enabling them to access ART treatment. This financial support came in a range of ways including lending money, looking after children financially, generating extra income by taking on extra work and housing the couples. A few couples added that they had no extra money to enable them to visit their families or siblings overseas leading to long gaps in seeing members of their family. Two Muslim couples felt responsible that they were not able to financially support their elderly parents which had in turn put strain on family relationships. Some couples also expressed family misunderstandings around ART especially with regard to egg or sperm donation which was culturally taboo. Some couples explained that in order to generate more income they had to work overtime or take on an additional job which took a considerable toll on family time.

With regards to social networks and friends, several couples confessed to feeling socially ostracized. They found that they could not afford to reciprocate social events

which led to falling out of social networks. Women admitted to feeling isolated from their friends who had children. A few admitted to not wanting to socialize with couples who had children as it was a negative reminder of their childlessness.

3.9.7 Lifestyle

Most couples commented on how paying for ART treatment had impacted negatively on their lifestyle causing a decreased standard of living. Several couples said that due to ART treatment they could not afford to go on holiday, either they did not have the spare funds to finance the travel or they were working continually in order to pay for ART, thereby not accessing their holiday time. One patient had even had to miss her siblings weddings as they could not afford to travel. Several participants said that they no longer had enough money for luxury items or to spoil members of their family or themselves with treats, presents, dinners out or weekends away. Some informants remarked on how they could no longer entertain or socialise with their friends as illustrated with this interview extract: "We don't see our friends unless they come to our house and bring food with them." A few married couples who had previously been independent of their families pointed out that they had to move back into the family home and be supported by their parents in order to fund ART treatment. One woman added that she would love to be a 'stay at home mommy' but due to the expense of ART treatment, she needed to work.

3.9.9 Education

Several couples remarked on how funding ART had had an influence on education, either on adult education or on children's schooling. As already mentioned, some couples had trouble financing their existing children's school fees, books, uniforms, school outings and extracurricular activities. A few participants admitted to having to stop their own studies, diplomas, degrees or courses in order to support ART treatment. One husband said he took out a bursary in order to keep studying and finance ART simultaneously. Another couple commented on the fact that they had no money for an education policy for their future children.

3.9.10 Future

Many couples spoke about future treatment and whether or not they would be able to afford to continue ART therapy. Several couples admitted that they would have to seek alternate funding. A few said such funding would be in the form of taking a loan from the bank or borrowing money, as well as curbing their lifestyle and basic household expenses further. Some couples confessed that this was the 'end of the

road' for their households that they would have to stop treatment as they were no longer able to finance ART and were financially "giving up". One couple disclosed that they had decided to adopt rather than continue with ART, while another couple said they faced childlessness as adoption was not culturally acceptable. Some couples displayed optimism and hope for a successful cycle and so were making plans to continue ART. Two couples were considering the expenses of a donor egg cycle in hope for a chance of having a baby. A few couples acknowledged that they would do anything for a baby and giving up on treatment, no matter what the financial implications were, was not imaginable.

3.9.11 Evaluation

A theme emerged that can best be described as an evaluation of the ART process and the cost of ART. Several couples felt that ART had been a "waste of time", that they had no child to justify their debt. In contrast, a few couples described ART as being worth it as they had had successful cycles. Several couples pointed out the lack of counselling they received with regards to the financial aspect of ART. They felt that patients would benefit from clear tabulation of all the costs involved, preferably in writing. Some couples stated that despite receiving a quote, there were hidden costs that they did not expect. A few expressed that they felt ART was like taking a 'gamble', illustrating the risk one takes financially on a small chance of falling pregnant and achieving your dream. One couple admitted that the expense of ART has put her off trying to conceive, while another couple felt that there should be more financial aid from the Governments. Some couples felt bitter that medial aids did not contribute to infertility treatment and felt that this needed to change.

4. Discussion

Fertility and infertility are central to reproductive health. The availability of infertility services therefore makes a relevant contribution to reproductive health. Owing to the underlying causes of infertility, ART is an important component of effective infertility treatment. Our study has shown that out-of-pocket payments for such treatment may have a negative impact on individuals and households. On the one hand people who may benefit from treatment may be prevented from accessing ART either by choosing less effective interventions with associated low success rates or by being forced into making alternative decisions such as acceptance of childlessness or adoption, not by choice but the lack thereof. Alternatively, couples who undergo ART may incur health costs with which they struggle to cope, a concept now well supported by the findings of this study.

Infertility is a worldwide problem, which has the highest prevalence in developing countries particularly in sub-Saharan Africa where infertile couples live with the overwhelming social, medical and financial burden of this disease.

To the best of our knowledge this is the first study from Sub-Saharan Africa which documents the financial impact of infertility treatment on individuals and households. Several important observations can be derived from our data.

4.1 Magnitude and Prevalence of Catastrophic Health Care Expenditure

Firstly, our results document that the frequency of catastrophic health expenditure, at 40% threshold, was 30% .That means that roughly one third of households in the study incurred catastrophic health care payments for ART treatment. At the lower threshold of 20 %, two thirds of households sustained catastrophic out-of-pocket payments.

There is no agreement in the literature regarding what threshold proportion of household expenditure is deemed catastrophic. In a study from Burkina Faso, the authors suggested that a single threshold, to determine catastrophic health expenses, may result in inaccurate estimation and misinterpretation (Su et al 2006). This was further supported by McIntrye et al (2006) who feels that various thresholds between 10% (as described by Ranson 2002) or 40% (as described by WHO world health report 2000) are arbitrary cut-off points, as much lower expenditure levels maybe catastrophic for poorer households (McIntrye et al ,2006). For the purpose of our study we used a higher threshold value of 40% and a lower

threshold value of 20% to quantify catastrophic health care expenditure for our study group.

We used household expenditure rather than income to determine catastrophic health care costs. The measurement of household income is inaccurate as household resources are diverse. Russell (1996) documented that there are data inaccuracies when household income is used. This is because monthly income is often multiplied to give an annual figure which does not take into consideration the variations of income per month. Furthermore, inaccuracies in income recall have been demonstrated by Pannarunothai and Mills (1996), who found that only 4/14 households, could give accurate accounts of income. Therefore it has been suggested that household expenditure should be used in research methodology rather than income as it proves to be less problematic (Russel, 2001).

In our study, total non-food household expenditure was calculated by asking patients to specify their monthly expenditure. This figure was then multiplied by 12 months. Itemized expenditure recall proved to be more accurate than using a general estimate of monthly expenditure. This approach has been used before. It has been shown that health costs are not smooth over time which has important implications for households coping and the impact that health costs have on households (Russell 2001; 2004). We anticipated that this approach would give a better representation of the impact that ART has on a household over a 12 month period than just in the index month of the IVF cycle.

To date there is no study that has looked at catastrophic payments and infertility. It is difficult to say whether our finding of catastrophic health care costs is in keeping with other studies as these have only looked at catastrophic health care relating to different diseases and settings.

A large multicountry analysis showed that the proportion of households in the general population facing catastrophic payments at the 40 % threshold for health care varied widely between countries, from less than 0.01% in Czech Republic and Slovakia to 10.5% in Vietnam (Xu et al, 2003). Developed countries are protected by social insurances or tax-funded health systems, thereby showing lower levels of catastrophic health care expenditure. In the analysis of ten developing countries including Brazil, Cambodia and Lebanon had catastrophic payments over 3%. South Africa's estimated proportion of catastrophic payments for health care was 0.03% which is comparable with Britain and Germany (Xu et al, 2003).

The study from Burkina Faso, to which I previously referred, documented catastrophic health care payments to be between 5-16% for households (Su et al, 2006). In coastal Kenya, catastrophic expenditure in the urban setting was 49.5% and in rural setting 47.2 %(Chuma et al, 2007). The percentage of households incurring catastrophic health costs varied from 3-3.5% in Sri Lanka and Thailand and more than 15% in Bangladesh. Catastrophic expenditure is almost 6% in Hong Kong and 11% in India (EQUITRAP Project, 2005). Researchers in Vietnam evaluated catastrophic payments for diarrhoeal disease. They showed that rich communities had a 26% out-of-pocket payment for health care while poorer communities had a 63% payment (Wagstaff and van Doorslaer, 2003). In Cambodia after a Dengue plague, households spent more than 50% of yearly per capita income on health care (Van Damme et al, 2004).

Caution must be exercised when comparing our results with these findings as these studies used a threshold of 10% of non-food expenditure to define catastrophic expenditure. Moreover, the studies mainly explored acute illnesses. If we used the same definition of catastrophic cost for ART treatment at a 10% threshold, the rate of catastrophic expenditure would have been 88.2%. A possible explanation for higher rates of catastrophic expenditure with regards to infertility treatment is that infertility is a chronic disease requiring specialised skills and medication. The average success rate is 30%, which means that infertile couples may require several treatment cycles, thereby requiring more out-of-pocket payments to achieve a success. In this context, chronic illness has been recognised as a risk factor for impoverishing health costs (Knaul et al, 2006; McIntrye et al, 2007).

4.2 Predictors of Catastrophic Health Care Expenditure

The incidence of catastrophic health care expenditure does not provide information on how catastrophic expenditures are distributed across households. Moreover, there is little data on household characteristics that identify households vulnerable to catastrophic payments. Identification of such characteristics would indicate which groups are most in need of protection against catastrophic costs. In our study we found three predictors of catastrophic expenditure: unemployment, no medical aid cover and a low level of education.

In the EQUITRAP Study (2005), household characteristics that were positively associated with catastrophic expenditure were household size, location, living conditions, households that had more women and children, lower level of education and employment status.

In our study, household size was not significantly related to catastrophic payments yet it is safe to presume that the household budget for health care should increase with household size. The possible explanation for this different finding is that infertility is not a communicable disease and only affects individuals. However if ART causes catastrophic costs then households, that have many members, will be vulnerable to these payments as the reduced available resources of that household are shared between all of it members.

In our study we did not analyse location. Location is, however, relevant to expenditures on health care as travel costs will raise expenditures. Several studies have documented that rural households incur more frequent catastrophic payments for health than urban households (Russell and Gilson, 2006; Chuma et al, 2007).

Education is negatively associated with the probability of catastrophic payments in all countries. A head of a household with a tertiary education is associated with a 34-60% reduction in the probability of catastrophic payments (EQUITRAP study, 2005). Higher levels of education lead to a better lifetime income and better living standards, which in turn reflects better health and, therefore, lowers health care expenditures. Our study supported this finding, as there was a significant relationship between a lower level of education and catastrophic payments for ART treatment.

Employment is similarly a protective factor as income will afford the household better living standards and protection from catastrophic expenditures. Our study is in keeping with the EQUITRAP study (2005) which reported that a working household head is 14-63% less likely to incur catastrophic health care costs (EQUITRAP, 2005).

In our study, the majority of households belonged to a medical aid scheme. In the group of households that were not covered, 63.3% incurred catastrophic health care costs. This is again in keeping with the EQUITRAP study (2005) which showed that households in Asia, that did not have medical insurance, sustained 40% catastrophic payments for health. Belonging to a medical aid can be a predictor of a higher socio-economic category which would in turn protect households from such health expenditures. Although medical aid schemes do not cover infertility treatment in our setting, households without medical aid have a double burden of paying for ART as well as other health care concerns.

4.3 Socio-economic Status of the Study Population and Poverty

The majority of participants belonged to a middle socio-economic category. The majority of households were equipped with basic amenities and lived in formal housing structures. The fact that the average households' monthly expenditure was calculated at R 11 872.71 and that the majority of couples belonged to a medical aid suggests a better income status, yet there was a wide range in monthly expenditure reflecting that there were poorer households amongst more well off households. Our data suggest that 16% of our study population fall into a lower socio-economic category. We hypothesize, that poor infertile people are not able to access the health care system.

Previous research showed that the distribution of public health services is unequal and the percentage of those with illness or injury who received health care varies widely by consumption quintiles (World Bank, 1993; Baker and Van der Gaag, 1993). Adding to this body of work, Makinen et al concluded that wealthier groups have a higher probability of obtaining health care when they need it, and there is an upward trend by quintile in health care use for those who report an illness. Makinen et al further established that wealthier quintiles were more likely to be seen by a doctor, receive medicines and spend more on health care then poorer groups. When specifically looking at a South African context, their research found that richer groups spend a higher proportion of their available income on health care then poorer groups. This was not the same for other developing countries included in their analysis which showed a reverse phenomenon where poorer groups were shown to spend more on health then richer groups (Makinen et al, 2000). This was further supported by McIntyre et al, who showed that in a South African study, households in the richest quintile were 2.3 times more likely to report illness than those that are in lowest-income quintile (McIntyre and Gilson, 2005).These findings are somewhat counter-intuitive given the high rates of ill health in the lowest socio-economic groups, and by ill health we can extend this to infertility as we do know that the burden of this disease is prevalent in the lower socio-economic groups.

Another way in which the economic costs of ill health can be avoided is by "modifying illness perception", the phenomenon of ignoring disease (Sauerborn et al, 1996).This idea was also postulated in the Kenyan study where half of chronic diseases were reported in urban and rural areas and did not receive regular treatment. This suggests that households choose not to seek health care rather than cope with impoverishment (Chuma et al, 2007). In a South African context, McIntyre et al (2007) showed that 27% of the lowest socio-economic quintile did not seek medical care, compared to 15% in the highest–income quintile. This concept can be

applied to infertility, were the infertile person may choose to accept childlessness and bear the negative psychosocial consequences of being infertile than face potential impoverishment.

There is evidence that out-of-pocket payments for health care and other economic consequences of ill health impose a greater burden on poorer families than on higher-income families (McIntrye et al, 2006). According to the methodologies used in other health equity studies, we divided our households up into socio-economic tertiles based on per capita household expenditure. It is fitting that we observed that the poorest tertile had the highest, 66%, catastrophic health care payments for ART. There were still high levels of catastrophic payments, 32%, in the middle tertile with the least burden noticed in the richest category at seven percent. This finding is not surprising as it has been well researched and documented that socioeconomic status is a key determinant of catastrophic health care expenditure in developing countries.

4.4 Direct Costs and Indirect Costs

Attention must also be paid to the varying aspects of direct and indirect costs of medical treatment. Direct costs refer to all financial payments made in seeking and obtaining health care. Indirect costs refer to the costs related to lost time and productivity. There is no consensus as to the amount that direct cost estimates impose on households as methodologies differ in the studies. Most studies have only put emphasis on the cost of health care and its service, while other studies have looked at other elements that may contribute to the direct cost, for example, transport to the health care facility. However, the majority of studies suggest that direct costs tend to be less than 10% of average household income (Sauerborn et al 1996, Lucas and Nuwagaba 1999, Makinen et al 2000, Russell 2001).

Indirect costs are less often measured than direct costs, due to the methodological challenges of obtaining accurate information. Studies that include both cost categories conclude that indirect costs of illness exceed direct costs (Koopmanschap and Rutten 1994). Some studies from developing countries suggest that indirect costs can be 2-3.6 times greater than direct costs (McIntyre et al, 2006).When direct and indirect costs of health are added, a total economic effect on households can be seen which is frequently above 10% of household income. For example, total household costs for malaria, annually, were as much as 18% in Kenya and 13% in Nigeria (Leighton and Foster, 1993).

There are only a few studies that attempt to quantify the indirect cost of ill health. They have measured indirect costs as number of days lost: the income the ill person and care giver were unable to obtain as a result of not being able to work or partake in productive activities. A study in India found that patients with chronic lymphatic filariasis lose up to 19% of work days a year (Babu et al 2002).

In the study, our finding of indirect cost is not in keeping with figures quoted in the literature. We calculated that households' indirect costs for ART treatment ranged from 5% of total economic burden in the index cycle to 12.6% in the previous cycles. However 41.2% of households lost work days during the index cycle.

The direct costs in our study far exceed the indirect costs. The direct costs, which included transport costs, were 95% of total economic burden in the index cycle, 87% in previous cycles of treatment at Groote Schuur and 93% in cycles obtained in private.

Analysing factors that contribute to direct costs of health, we see that medicines, transport, location, accommodation, nutritional food and care givers are often mentioned and add to a sizeable share of the direct costs. Medicines account for more than 60% of direct costs in the treatment of malaria in Ghana (Asenso-Okyere and Dzator, 1997).Similarly, drugs contributed 63% of the costs for treating lymphatic filariasis in India (Babu et al, 2002). In a normal vertex delivery in Bangladesh, drugs add 39% to direct costs and 55% for caesarean deliveries (Nahar and Costello, 1998). Russell found in Sri Lanka that 33% was an average figure for all direct costs irrespective of disease type (Russell, 2001). The cost for ART drugs in our study, as a proportion of our direct costs, were in keeping with the proposed figures in the literature. For the index cycle the mean cost of ART drugs per cycle was R 8000 and therefore accounted for 69.4% of the direct costs.

It has also been found that transport costs for the ill person and that of the accompanying person are not insignificant and account for 14% and 20% of direct costs in the case of malaria in Ghana and Sri Lanka respectively (Asenso-Okyere and Dzator, 1997), 20% of that for maternity care in Bangladesh (Nahar and Costello, 1998) and 14% on overall health care in Sri Lanka (Russell 2001). The transport costs in our study were not a significant portion of the direct costs accounting for 1.13% in the index cycle to 5% in previous cycles. This is likely due to the fact that our urban clinic serves the surrounding community, thereby reducing transport costs.

4.5 Coping Strategies

To manage the impact of ART treatment costs, households had to initiate coping strategies. Some of these coping strategies have short term effects while others like reducing spending on educating existing children, may have long term consequences.

This study identified some key issues with regard to coping strategies. Firstly, a similar pattern of coping strategies were adopted in the index cycle to the previous ART cycles. Regarding reduction on household spending, we again see similar trends in what commodities were decreased between the index cycle and previous ART cycles. Initially nonessential items were reduced, starting with clothing and entertainment which encompasses luxury items, holidays and socialising. After these reductions were made, then essential commodities such as food, education of children and rent were decreased. These coping strategies will be discussed individually with the supporting evidence from the literature.

4.5.1 Reduction on Household Spending

A central coping strategy used by all the households were 'cut backs' , placing restrictions on luxury items, food, water, electricity, petrol, public transport, clothes and entertainment in order to generate extra money. Our finding was in keeping with a report by McIntrye et al (2006) which found that in the event of unavailable cash or savings, the coping strategy adopted was reduction on consumption of food. In contrast, previous studies have suggested that borrowing money is the commonest coping strategy used in financing health care. A possible reason for the observed discrepancy is that the majority of these studies were done in very poor countries (e.g. Vietnam, Sri Lanka, Sierra Leone, Cambodia and Burkina Faso) where "cutbacks " on nonessential and essential items have already been made and where further reductions in household spending cannot be made.

4.5.2 Accessing Savings

The second most immediate response to paying for ART was to use available cash and to mobilise savings. We found two models of financing treatment. Younger patients adopted a 'save-spend-save' model of paying for treatment which resulted in delays between treatment cycles but with less debt. Older patients who felt that time was against them, accessed their savings, but if subsequent cycles were needed they continued to pay for treatment even if it meant going into debt. This is the 'save-spend-spend' model. In the literature there is conflicting evidence

regarding this coping strategy. In the Sierra Leone survey (1996), it was noted that using available savings only satisfied the minority of households as the majority actually did not have surplus money to pay for health care. This lack of available funds deterred ill people from seeking health care (Russell, 1996; Sauerborn, 1996). Other studies from Kenya and Sri Lanka found that households did have enough available cash to pay for the direct health costs for acute and chronic health issues (Chuma et al, 2007; Russell, 2001; Tibaijuka 1997) .Caution must be used in comparing these studies to our own, as they deal mainly with acute illness episodes and do not give any interpretation into how households mobilize their savings and what happens over time. Through the two models of financing ART our study has given new insight into how couples have accessed their savings in order to fund ART treatment. Our study concurs with the Kenyan and Sri Lanka study, showing that households did have available savings to access infertility treatment.

4.5.3 Borrowing Money

In our study, borrowing money was the third adopted coping strategy for the majority of households. Our findings differed from the literature, where studies documented that borrowing money was the most common response to coping with health costs. These loans are often informal, given from friends, family or a moneylender, highlighting the importance of social networks (Sauerborn, 1996; Russell 1996, 2001, 2004). Van Damme et al (2003) showed that 59% of Cambodian households borrowed money and 43% of those loans were from a moneylender. This was further supported by a study in Serra Leone where 44% of households made claims on family while 1.7% borrowed from a moneylender (Russell, 1996). Our study did not support this previously observed coping strategy as those households that borrowed money took formal loans from the bank and did not use social networks to help finance ART treatment. Several hypotheses can be drawn from this altered finding. Owing to the silent nature of infertility, couples possibly took loans out from the bank thereby not sharing their problems with family or those family members who may be unsupportive of the couple's infertility diagnosis. Those households that took loans from the bank may also be in a better financial position to make loan repayments thereby highlighting a more well off community of people that come forward for IVF treatment then, say, those households who have arranged informal loans where the repayments may have been negotiated on less strict repayment terms. It is also possible that couples choose loans from a neutral third party rather than be indebted to family or friends which have the potential to put unnecessary strain on relationships.

The qualitative data from previous studies described that borrowing money was the preferred coping strategy as it was the quickest way to raise money. Strategies, such as selling assets, required time to get a buyer and to fix an acceptable price, thus potentially causing delays in getting treatment as well as low prices for the asset in question. These studies show the thinking that it is better to borrow than to lose asset value when you are in need. It is therefore more advantageous, even for the wealthy, to take on a loan than to sell an asset (Chuma, 2007, Mugisha, 2002). The sale of an asset over time will allow the right price for that asset rather than accepting lower prices. Borrowing and lending is done on honour and trust that the loan will be repaid. Loans can be potentially devastating to households' livelihood. They are influenced by the character of the loan-giver, the terms of the loan and interest rate which can be ruining. Loans from family or friends can also place strain on relationships.

4.5.4 Extra Work

Another strategy for dealing with the direct cost of health care are for family members to take on extra work to generate income (Sauerborn, 1996). In our study this was a common coping strategy adopted by households and agreed with general observations in the literature. Family members had to take on extra work, second jobs and overtime to produce more funds for ART treatment. A different set of strategies are used to cope with the indirect costs of ill health. Our study concurred with the findings of the Kenyan study which showed that families, helped finance ART indirectly by housing couples, sharing in household expenses, looking after children, reallocating household chores among able family members and helping with transport (Chuma, 2007).

4.5.5 Selling Assets

Selling assets was not the preferred coping strategy, especially when the asset is an integral part of the households livelihood or if it is productive. We found this to be accurate for our study too, as it has the potential to set a cycle of impoverishment for that household. The minority of households were forced into selling assets that ranged from houses to cars to leave days. A sale of a productive asset suggests that the household has reached its critical threshold in its capacity to cope (ability to pay) having exhausted all other less economically impoverishing coping strategies (Russell 1996). This is true as we observed a significant association between the selling of an asset and incurring catastrophic health costs.

4.5.6 Delayed Payments

In our study we observed that many households delayed payments of accounts, rent and utilities. Some households even delayed loan repayments**.** It is difficult to decipher if this is a true coping strategy or as a result of the financial impact of ART treatment. Delayed payments are a coping strategy that has not been well researched. There is only one study from Ghana where traditional healers and drugstores were used in preference to government facilities as treatment could be paid in kind or by credit (Russell 1996). This has no bearing on our study as patients needed to pay for their treatment prior to commencement of ART, thereby supporting the idea that the delayed payments were as a result of financing ART rather than a mechanism to access ART.

4.5.7 Type of Health Care Facility

Another coping strategy used is the type of health care facility a household uses. Russell (2006) demonstrated that Sri Lankan people, who used public health facilities, were better protected from health care costs than those that used private health care providers. Owing to subsidized ART treatment, we observed a lesser average cost per cycle. It is then self explanatory that those households that chose to have treatment at the Groote Schuur Infertility Clinic would be protected from health care costs compared to those households that have treatment at a private facility. One couple mentioned that one of their coping strategies was to come to a public ART clinic were treatment was cheaper than a private facility thereby ensuring more treatment and by reference more of a chance of a successful pregnancy. The main reason for discontinuation of ART treatment at private facilities was expense.

4.5.8 Consequences of Financing ART: Emotional stress and Financial Stress

The negative effect of infertility on the reproductive health of men and women in Africa is gradually being recognised. There is good evidence that infertility causes emotional stress (Goldfarb, 1997;Domar, 2004;Olivius, 2004;Dyer ,2005) which increases with an increasing number of cycles and unsuccessful pregnancies (Rajkhowa et al,2006). A study that looked at reasons for discontinuation of ART found that 36% cited psychological stress as the reason for stopping treatment (Rajkhowa et al, 2006). In an Australian study, where six cycles are financed by the state, an average of only three cycles were undertaken, suggesting that a lack of

funding was not the sole reason for discontinuation of treatment (Hammerberg et al, 2001).

In support of ART causing financial stress, Klonoff-Cohen et al (2004) showed that at the start of an ART cycle, 20% of women were concerned about missing work and 33% were worried about finances. After a cycle of ART, the women who had been concerned about finances had an 11 odds risk of not having a successful live birth then those who were not concerned with finances. The study also showed that women who were worried about missing work had twofold odds of not achieving a pregnancy compared to those women not concerned about missing work. Discontinuation for financial reasons increased with the increasing number of cycles (Klonoff-Cohen and Natarajan, 2004).

Little is known as to what extent ART causes financial stress and to what extent male partners feel stress. We measured emotional and financial stress using a five point Likert-scale assessing stress from minimal to extreme stress of both men and women. There is no standardized or specific instrument for assessing ART-related stress. Rather there are standardized psychological instruments adapted first to infertility-related stress and recently to ART-related stress using the CART questionnaire (Klonoff-Cohen and Natarajan, 2004). This questionnaire assesses stress also using Likert-scale of concern.

Our findings were that there were slight gender differences between the overall emotional stress with women feeling more emotionally stressed than financially stressed in the extreme category where as men felt more financially stressed than emotionally stressed for the same category. This gender difference was not statistically significant. Emotional stress in both men and women was higher than financial stress; however, we observed high rates of both financial and emotional stress. Financial stress and emotional stress were both not significantly associated with catastrophic expenditure. An explanation for this finding is that even in households that do not encounter catastrophic payments for ART, they still have high health costs that cause significant financial stress.

We also observed, that some couples undergoing repeat cycles experienced higher levels of financial stress in the subsequent cycle. This finding agrees with previous studies which found increasing emotional and financial stress with the increasing number of cycles (Rajkhowa et al, 2006; Klonoff-Cohen and Natarajan, 2004). However, our study indicates that financial stress is of greater concern than emotional stress in repeat cycles.

4.6. Qualitative Findings

By means of an open-ended type of question (Question number 29, please see questionnaire in Appendix 1) couples were able to spontaneously share their experience on how their households had been affected by ART treatment. Even though certain themes were not mentioned or commented on by all the couples it did not mean that aspects of the themes were not experienced for that particular household.

The main theme identified in our qualitative data analysis was that out-of-pocket payment for infertility treatment had caused financial stress. This result supports our quantitative finding.

Concern regarding the sacrifices that the households had made in order to finance ART was the next most common theme. Couples described a general pattern of scaling down: initially not being able to afford luxuries, to not being able to afford the basics. Opportunity cost all have important implications on financial security which is potentially threatened by ART.

Emotional stress was also a common theme but not spontaneously mentioned to the same magnitude as financial stress. The main emotion expressed was the deep desire to be parents as well as disappointment of unsuccessful cycles. Of concern was a high level of admitted depression, sadness and anxiety which centred on the possibility of facing childlessness either through repeated unsuccessful cycles or having to discontinue treatment due to financial pressure. These expressed feelings tie in with previous research by Davis and Dearman (1991) where infertile women from America reported intense feelings of sadness and frustration at not being able to conceive.

The next most common theme mentioned was the impact that ART had had on relationships both with their partners and with extended family and friends. Many couples reflected that ART is a stressful event for a couple to experience and it does cause strain on relationships. This is a relative finding as social networks may protect households from being vulnerable to health costs as they assist in accessing sources of credit, help with substitution of labour and they play a role in community saving schemes or ‘stokvels’ (Ranson 2002). Households form an important adaptive foundation for the poor by pooling income and other resources, sharing consumption, redistribution of income and security.

Another important consequence of ART was the social exclusion. This was either through having a limited household budget to afford to entertain friends or forced isolation where infertile couples did not want to socialise with other people who had children as this was a painful reminder of the childlessness. Avoidance has been investigated as a coping strategy among infertile women and is correlated significantly with emotional stress (Blenner, 1992; Stanton et al, 1992; Morrow et al, 1995; Donkor and Sandal, 2009).

An important theme identified was the impact that ART has had on existing children and their education. Central to this theme, was the redistribution of available money, which was initially spent on existing children, so that they could finance ART. A potential long term impact of financing ART was that reductions were made to children's school fees or extracurricular activities thereby depriving children of vital education and stimulation. In some cases children stopped attending school due to the parents not being able to pay for the tuition. In sub-Saharan Africa, girls especially may be taken out of school to accommodate for ill family members thereby threatening their education and long term economic security (Mutangadura et al, 1999; Russel, 1996).

In the open-ended question, patients evaluated the ART process and the cost of treatment. Unsuccessful couples felt that ART had been "a waste of time" as they had nothing to show for their debt. Others praised the treatment as they had had a successful pregnancy. Couples criticized the lack of counselling with regard to the financial implications of ART by the providers. They felt this was a short coming and better financial insight would have helped them be in a better financial position.

In summary, we observed that ART treatment is financially and emotionally stressful. The effect of ART treatment has important impact on relationships. Couples make sacrifices in order to finance the cycles. The implications of ART treatment include decreased standard of living to loss of financial security, depression and neglect of existing children. Is all this strain worth it? Those that have had a successful cycle say yes as no price can be placed on having a child. Those that remain unsuccessful in achieving this goal have expressed that ART is a waste of time. It is imperative to offer couples both psychological support and solid financial insight before and during ART treatment. It is even more important to continue this counselling into subsequent cycles, as it has been demonstrated in our study and other already mentioned studies that financial stress increases with increasing cycles. Whether counselling alleviates financial and emotional stress still needs to be evaluated.

5. Liitations

This is a small study yet it offers insight into catastrophic health expenditure with regard to ART, an area not previously researched. This study is essentially an interim analysis for an ongoing study which aims to analyse a 150 ART cycles.

There will always be error in calculating catastrophic expenditure due to lack of accurate documented financial information. There will also be inaccuracies when calculating catastrophic expenditure using income, as income per month does not allow for monthly variation of household income. Literature has shown that using household expenditure as a proxy for income is less problematic. However household finances and health costs are not consistent over time which has important implications for financial impact and calculating catastrophic expenditure.

One should be aware that data obtained on out-of-pocket payments, opportunity costs and coping strategies for previous ART may require a long recall period. ART is a significant life event and is likely to leave a clear memory imprint, especially if catastrophic costs were incurred.

The study was not able to define the socio-economic profile of our study population due to the inability to gain access to the Western Cape Community Survey. We are therefore only hypothesizing that the poorest groups of people in our community are not accessing ART treatment. In the future we will be able to access this survey data and accurately define our study population and thereby answer this question.

With regard to the 10 repeat cycles included in our study, it can be argued that they added little to the results. The socio-demographic and infertility variables remained unchanged between the index cycle and the repeat cycle and therefore the data derived from the repeat cycles was excluded in order to avoid repeated variables being counted twice. With regard to the rest of the analysis, the repeated variables were included as we felt that they could have had bearing on our main study questions with regard to catastrophic out-of-pocket payments as well as the impact that it had on those households in this body of work. We had anticipated more households to undergo repeated cycles. This would have shown a greater than occurred change in household circumstances and an impoverishing spiral. With the larger study sample, more repeat cycles will be incorporated and analysed with regard to catastrophic costs and its impact on households.

Consensus answers were recorded but capturing areas of disagreement especially with regard to views would have made the data richer. Consensus answers were

mainly taken with regard to factual information about finances, expenditures and assets in order to make analysis easier. Individual answers were however recorded for ART related emotional and financial stress.

An open-ended question was used to capture patient's spontaneous views and feelings related to ART costs, ART related financial and emotional stresses as well as the coping mechanisms that households adopted. These responses were then placed in themes following some qualitative research principles, yet a true qualitative analysis was not performed. A more in-depth study was not considered for this study since this would usually receive fewer informants in a qualitative survey of this nature.

As there is no previous research done on the extent and impact of catastrophic health expenditure caused by ART treatment on households, we therefore had no data to compare our study. There are few studies that have attempted to analyse various aspects of catastrophic expenditure, hence the repeated reference to these studies.

6. Future Research

This dissertation presents interim findings of an ongoing study evaluating catastrophic health costs and the impact of ART related cost which aims to analyse a 150 ART cycles.

These interim results and ongoing study have and are generating novel findings related to infertility in South Africa. Our research question has generated numerous questions. Some of these are:

- What is the time frame to financial recovery for households that have faced catastrophic health care costs?
- What percentage of households does not financially recover from these costs?
- A more in depth qualitative analysis, with a selective group of patients, would give deeper insight into households OPP, coping strategies as well as ART related financial and emotional stress.

The data needs to be analysed in relation to the Western Cape survey in order to define the socio-economic profile of the study population and thereby assess who is accessing ART. Our research has shown that a better resourced sample is

accessing ART and not poorer communities, reflecting inequalities in accessing infertility treatment in South Africa at large.

7. Conclusion

ART related out-of-pocket payments created a heavy financial impact on households reaching catastrophic proportions for at least one in three households. Couples adopted a range of financial strategies which may have long-term impact and potentially impoverish the household. We observed that the consequences of ART treatment are a high level of both emotional and financial stress and deduce that couples facing ART-related costs require counselling on the impact of their treatment.

It can be concluded that while infertility services are essential to the reproductive health of both men and women, the associated need for out-of-pocket payments may compromise the benefits that can be gained from these services. This impact may prevent couples from undergoing repeat ART or from accessing treatment. We have documented that a lack of funding for ART creates inequalities and inequities in reproductive health care. The findings of this study are relevant for health care planners and highlight the problems in reproductive health funding in South Africa.

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Appendix **1**

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:

D: Ethnicity		**F: Relationship to head of household**		**G: Highest level of education**		**H: Employment Status**
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
E: Place of birth		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 Groote Schuur?**

Yes	1	No	2 →	If no, go to Section D

9. ***If yes*, where did you seek care previously and in what year(s)?**

Private hospital	1	Other public hospital	2

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 1I), 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? Relative = 1 Friend = 2 Employer = 3 Bank = 4 Other money lender = 5 Other [specify] = 6	**Code**	**If other, specify**

2c Did you have to pay interest on this loan?	Yes = 1	No = 2
2d 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
3a If yes, who did you receive financial assistance from? Relative = 1 Employer = 3 Friend = 2 Other [specify] = 4	**Code**	**If other, specify**
4. Did you have to sell any assets?	Yes = 1	No = 2
4a If yes, what type of assets? Jewellery = 1 Car = 3 Household goods (e.g. TV) = 2 Other [specify] = 4	**Code**	**If other, specify**
5. Did you have to reduce spending on other household items?	Yes = 1	No = 2
5a If yes, what household items did you have to reduce spending on? Food = 1 Education = 4 Rent (e.g. move to cheaper area) = 2 Entertainment = 5 Clothing = 3 Other [specify] = 6	**Code**	**If other, specify**
6. 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?**

Yes	1	No	2

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
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? Relative = 1 Friend = 2 Employer = 3 Bank = 4 Other money lender = 5 Other [specify] = 6	**Code**	**If other, specify**
2c Did you have to pay interest on this loan?	Yes = 1	No = 2
2d 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
3a If yes, who did you receive financial assistance from? Relative = 1 Friend = 2 Employer = 3 Other [specify] = 4	**Code**	**If other, specify**
4. Did you have to sell any assets?	Yes = 1	No = 2
4a If yes, what type of assets? Jewellery = 1 Household goods (e.g. TV) = 2 Car = 3 Other [specify] = 4	**Code**	**If other, specify**
5. Did you have to reduce spending on other household items?	Yes = 1	No = 2
5a If yes, what household items did you have to reduce spending on? Food = 1 Education = 4	**Code**	**If other, specify**

Rent (e.g. move to cheaper area) = 2 Entertainment = 5 Clothing = 3 Other [specify] = 6		
6. 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
Sperm problem	2
Failure to ovulate	3
Age-related fertility problem	4
Endometriosis	5

Unexplained infertility	6
Failure of other infertility interventions	7
Indication not known by respondent	8
Other (please specify below)	9

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 1I), 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

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

26. **During the current treatment cycle, have you lost any income through taking time off work, reducing the number of hours worked or giving up your job?**

Yes	1	No	2

27. **How did you manage to pay for the costs incurred by the current ART cycle at Groote Schuur** [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? Relative = 1 Bank = 4 Friend = 2 Other money lender = 5 Employer = 3 Other [specify] = 6	**Code**	**If other, specify**
2c Did you have to pay interest on this loan?	Yes = 1	No = 2
2d 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
3a If yes, who did you receive financial assistance from? Relative = 1 Employer = 3 Friend = 2 Other [specify] = 4	**Code**	**If other, specify**
4. Did you have to sell any assets?	Yes = 1	No = 2
4a If yes, what type of assets? Jewellery = 1 Car = 3 Household goods (e.g. TV) = 2 Other [specify] = 4	**Code**	**If other, specify**
5. Did you have to reduce spending on other household items?	Yes = 1	No = 2
5a If yes, what household items did you have to reduce spending on? Food = 1 Education = 4 Rent (e.g. move to cheaper area) = 2 Entertainment = 5	**Code**	**If other, specify**

Clothing = 3 Other [specify] = 6		
6. Did you or other members of your household have to take on extra work to try to generate extra income?	Yes = 1	No = 2

28. **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)					

29. **Could you please describe in your own words how the costs of ART have impacted on your household, if at all? Do you feel that these costs have adversely affected your livelihood and if so, please explain how you have experienced this?**

30. **How would you describe the financial impact of ART on the household?** [SINGLE MENTION]

Minimal	1	Burden that the household is still recovering from / struggling with	4
Household managed easily	2	Household unable to cope, and its survival is threatened	5
Household copes, but with difficulty	3		

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
6. not at all		
7. a little bit		
8. moderately		
9. quite a bit		
10. extremely		

F. Household Socio-Economic Information

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

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

Formal	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
Informal	Informal dwelling/shack, NOT in backyard	7
	Informal dwelling/shack, IN the backyard of a formal house	8
Traditional	Traditional dwelling/hut/structure made of traditional materials	9
Other	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

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.**

	Yes	No	
1. Ordinary (Telkom) telephone	1	2	← If no, go to 3
2. ***If yes***, Is this prepaid? (Code 1 for prepaid; i.e. 2 for account)	1	2	
3. Cell phone	1	2	
4. ***If yes***, 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	← If yes, go to 9
9. ***If yes***, how old is the newest car / truck / bakkie in your household since the date of manufacture [SPECIFY AGE IN YEARS]			

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]

Income category		***No. of people in household receiving…***
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]

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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 **2**

Clinical and Financial aspects of the ART cycle

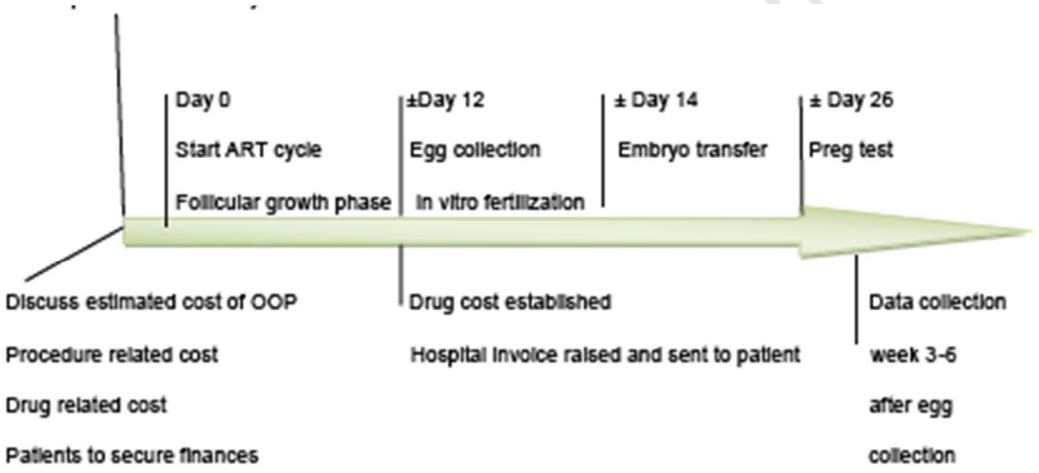
(Diagram not drawn to scale)

Clinical Timeline

Consultation

Discuss ART

Inform patients of the study



Financial Timeline

Patient Information Sheet

The Assisted Reproductive Technologies (ART) Cost Study

Researchers at Groote Schuur Hospital and the Faculty of Health Sciences would like to study the implications of out-of-pocket payment made by patients in order to undergo an IVF (in vitro fertilization) cycle. We also call this treatment ART, which means Assisted Reproductive technologies, and which is the same as IVF or 'test tube baby treatment.'

The aim of the study is to explore how patients undergoing IVF at Groote Schuur Hospital Infertility Clinic cover the costs of their treatment, what sacrifices they make and what plans were made to raise the money. We are doing this research as we are concerned that for some patients IVF treatment may cause financial hardship for the couple and perhaps the extended family. We hope that the findings of this study will allow us to better prepare patients for IVF treatment in future, and perhaps we may even be able to influence the hospital/medical aids to provide better funding for this form of treatment. In addition, this study will help one of the researchers to obtain a higher academic degree, namely a Master of Medicine (MMed).

We would like to include you in the study so we can learn from your experiences and hear about the financial difficulties you may have faced. We would very much like to include both you and your partner, but if either of you do not wish to be part of the study, you or your partner can participate on their own.

We would be grateful if you could spare us about half an hour of your time to answer our questionnaire. If at any time you feel uncomfortable to answer a question, you may withhold the answer. Anything you say 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. 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.

Please note that while we are not able to reimburse you for taking part in the study, we are willing to cover any transport costs to and from the hospital on the day of the interview.

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.

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. Alternatively you may contact the Human Ethics Committee in room E52-24 Groote Schuur Hospital Old Main Building or phone 021-406 6338.

Patient Consent Form

The Assisted Reproductive Technologies Cost Study

I, ... 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 then the members of the research team.

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

Date:.....

Signature:.....

Witness:.....