

A qualitative study of the experience of treatment for infertility among women who successfully became pregnant

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BACKGROUND: In a study in which 18 503 women who had recently given birth were interviewed, 460 women who had received treatment for infertility (2.6%) were asked to participate in a postal study. The aim was to investigate the experience of women who had undergone treatment for infertility and given birth as a consequence, focusing on perceptions of treatment and care. **METHODS:** The study relies on responses to open-ended questions about the impact of treatment, how treatment could be improved and advice to policy makers. The text responses to these questions were analysed qualitatively. **RESULTS:** A total of 230 women responded (50%). Emergent themes related to the treatment process, pain and distress, lack of choice and control, timing, emotional and financial costs, fairness and contrasts in care. **CONCLUSIONS:** Women wished to be treated with respect and dignity and given appropriate information and support. They wanted their distress recognized, to feel cared for and to have confidence in health professionals in situations where outcomes are uncertain. Women acknowledged receiving care from motivated and skilled health professionals and value the children they have enormously. For many, there is now a sense of being complete, though for some this has been at great emotional and financial cost.

Key words: infertility/infertility treatment/qualitative methods/women's perceptions

Introduction

The experience of infertility and involuntary childlessness and attempting to overcome that state is part of a dynamic process, with a different trajectory for each individual (Connolly *et al.*, 1987; Woollett, 1991). Perspectives vary with age and life stage and individuals' stories and timing differ, though at the core is an imagined or projected sequence from planning a pregnancy through to having a live baby. The pace and manner in which a woman and her partner move through the phases varies and different experiences are likely to impact on the way that treatment is perceived.

Psychosocial studies have focused on the impact of investigations, on the counselling of infertile couples (Connolly *et al.*, 1993), on the decision to end treatment (Peddie *et al.*, 2005), on responses and adjustment to being childless (Jones and Hunter, 1996; Daniluk, 2001) and on staff views of treatment (Porter and Bhattacharya, 2005). Concern has been expressed about the impact of fertility treatment and the way it may affect how a pregnancy is experienced subsequently (Woollett, 1991; Burns, 1996). It has also been argued that some behaviours, for example, a reluctance to discuss potentially negative aspects of pregnancy and parenthood, lower levels of information-seeking and less-active preparation for childbirth, may be elements of protective coping strategies following treatment rather than inadequate

adjustment (McMahon *et al.*, 1999). Studies of psychological well-being, using a range of standard instruments and designs, have provided quantitative data on levels of anxiety and depression, and the impact on couples' relationships, some concurrently and some in retrospect (Slade *et al.*, 1997; Hammarberg *et al.*, 2001). Few studies have used a qualitative approach in investigating the experiences and attitudes towards treatment of women for whom treatment for infertility was successful. The aim of the present study was to increase the understanding of how women experience treatment and care by using their own words as the starting point and to indicate ways in which practice and care might be improved.

Materials and methods

This study forms part of the Millenium Cohort Study (MCS), a longitudinal research programme on a nationally representative sample of infants who were living in the UK at 9 months of age and who were on the child benefit register (Dex and Joshi, 2005). Children and families living within disadvantaged wards, with more than 30% ethnic minority households, were over-sampled; however, the descriptive data presented here are unweighted. A response rate of 72% was achieved overall and a total of 18 503 women who had recently given birth were interviewed, 460 of whom (2.5%) reported having received medical treatment for infertility leading to the index birth included in the

study. A semi-structured postal questionnaire was sent to this group, which asked more detailed questions about the nature of the treatment or treatments received and the financial costs incurred. The following open-ended questions were used in this study: How disruptive was receiving fertility treatment to your life? In what ways could your experience of infertility treatment have been improved? What, if anything would you like to tell policy makers in the National Health Service (NHS) or government about your experiences of infertility treatment? Please use the space below to add any more details to any of your answers or tell us about anything else that you would like to about your infertility treatment. The aim was to encourage participants to articulate their experience of treatment in their own terms.

The text responses to these questions were analysed qualitatively using thematic analysis, with initial codes then being used to create higher order categories (Carter, 2004). The categories were refined in the course of reading and re-reading and continuously checking the data for counter-examples and alternatives. With each re-reading, new insights occurred and it became possible to make associations and connections between different aspects of the data. Key words and phrases were noted, and as themes emerged and connections were made in a cyclical progression, they were re-grouped in a process similar to that utilized by other researchers (Dyer *et al.*, 2004; Peddie *et al.*, 2005). The process was repeated with each set of responses. The analysis also aimed to map and highlight the dimensions and context of the language used, identifying rhetorical devices, such as metaphor, that reflect social meaning. As de Lacey (2002) points out, in nursing and health care, metaphors are used to frame disease and practice. Using such methods a common sense understanding is conveyed, health problems, procedures and treatment can be normalized and made familiar, while at the same time often reinforcing power relationships. Quotations are used to illustrate the themes generated by the analysis, to support the

interpretations made and to demonstrate the metaphors that appear to be operating in this context (Henwood and Pidgeon, 1992). The responses to the questions about improvements in care and what the respondents would like to say to policy makers were also used to generate quantitative data in a more formal way: the responses were read, a list of topics were generated, each response was coded for up to three topics and the numbers and proportions for each topic were calculated.

Demographic data used to describe the group and to make comparisons with non-responders come from quantitative analyses using the main MCS interview data.

Ethics

The Cohort Studies Code of Practice covers all those working with MCS data, including that arising from this substudy. Research ethics approval was sought and obtained from the South-West Multi-Centre Research Ethics Committee.

Results

The study respondents

A total of 230 eligible women responded to the postal questionnaire, representative of a 50% response rate. The responders were compared with the non-responders (Table I). Responders were more likely to be married, white, of a higher social class and better educated. However, responders and non-responders were similar with respect to maternal age at the birth of the cohort baby, previous living children, time taken to conceive and type of treatment. As with the main MCS, analysis of

Table I. Characteristics of responders and non-responders to the postal questionnaire

Maternal characteristics	Responders (<i>n</i> = 230) (%)	Non-responders (<i>n</i> = 230) (%)
Maternal age at birth of index child (mean) (range)	32.7 (20–51)	31.9 (17–48)
Marital status		
Married	85.2	78.7
Cohabiting	10.4	16.1
Lone parent	4.4	5.2
Ethnicity		
White	96.1	84.8
Non-white	3.9	15.2
Social class (NS-SEC)		
Managerial/professional	48.3	35.6
Intermediate	5.2	4.4
Small-employer/self-employed	11.7	9.6
Lower supervisory/technical	11.3	13.5
(Semi-)routine	10.0	16.5
None of these	13.5	20.4
Education (NVQ level)		
Higher (NVQ 4 and 5)	49.1	36.1
Medium (NVQ 3)	13.5	15.6
Lower (NVQ 1 and 2)	31.7	31.7
Overseas/other	0.9	2.6
None of these	4.8	13.9
Previous living children	41.0	38.3
Time taken to get pregnant (years)		
Median (range) (years)	3 (0–15)	3 (0–14)
Percentage of who took ≥5 years	22.6	23.4
Infertility treatment		
Ovulation induction only	42.2	46.1
Non-ART surgery (with or without ovulation induction)	10.9	10.9
ART (including DI, IUI, GIFT, IVF and ICSI)	47.0	43.0

ART, assisted reproduction techniques; DI, donor insemination; GIFT, gamete intra-Fallopian transfer; IUI, intrauterine insemination; NS-SEC, National Standard Socioeconomic Classification; NVQ, National Vocational Qualification.

responses on infertility involved data provided by women who were successful in achieving a pregnancy and a cohort baby surviving to >9 months of age. Throughout the women's responses, their success is acknowledged and this may be a central factor in the kind of experiential material they provide. What they have to say about the treatment that led to the birth of the MCS baby and the way that they frame their experiences offer insights about this aspect of health care and provision from the perspective of this particular group and for infertile couples more broadly. Although what is being said is in the context of success, this may have been at the end of a series of failures, and for some women, there was the prospect of repeating the experience again with all the same uncertainties about outcome.

It has been suggested that responses to open-ended questions at the end of surveys about maternity care may be biased towards those women having more adverse experiences (Garcia *et al.*, 1998) and it may be that this kind of group was over-represented among the respondents to the present survey. Thus, it might have been expected that the proportions of women having different types of treatment for infertility would differ between respondent and non-respondent groups, for example, with more women responding who had experienced surgery or assisted reproduction techniques. This was not found to be the case. In the IVF study by Hammarberg *et al.* (2001) looking back after quite a long time interval, those women who had not become pregnant felt worse about their experience, though on many points, such as missed career or job opportunities, regrets associated with IVF treatment and preoccupation with IVF treatment, the views of the 'Baby' and 'No baby' groups coincided.

The response rate of the non-white portion of the population of women having a successful pregnancy following infertility treatment was significantly different, with Asian women being least represented. This bias should be borne in mind as it may have reduced the range of experience documented in the study.

A total of 43% of responders had received treatment for infertility before that which led to the index birth. Among the responders, responsibility for infertility was most commonly ascribed to the female partner (61%) and less often to the male partner (13%), both partners (4%) or else was unknown (21%). Relatively few of the group who received ovulation induction (42%) and of those receiving surgery (11%) paid for some or all care in the private sector (16 and 5% respectively). This contrasts with those in the group who received IVF and related procedures (47%), of whom more than three-quarters (79%) paid for treatment. Mean costs for an individual treatment varied considerably, ranging from £47 for ovulation induction to £4318 for one cycle with ICSI, and one individual reported spending a total of £17 000 on fertility treatment. Distances travelled for treatment also varied, and a round trip to their last appointment involved a mean distance of 41 miles (median 16, range 1–700 miles).

Infertility and the role of luck

The dominant themes are listed in Table II, the first of which is luck and good fortune. The role of chance for the group in this study was seen as powerful, and there are many references to

Table II. Themes arising from women's perceptions of the infertility treatment process

Emergent themes

The role of luck and good fortune
Lack of choice and control
Emotional and physical pain
Becoming a non-person
The need for stoicism and sacrifice
Number and measurement
Lost and wasted time
Differences in care
Financial and emotional costs
Fairness and equity

fortune at all stages in addressing their fertility problem. This was in terms of being 'lucky', living in the 'right' place, picking a sympathetic general practitioner (GP) or specialist, contacting the 'right' clinic, in receiving an effective treatment and in having a positive outcome. Linked with this is the construction of the resulting child or children as a prize. However, women in this study also saw themselves as working hard for the hoped for reward or outcome, putting in time and effort, overcoming obstacles, enduring discomfort and surmounting difficulties (Franklin, 1990, 1997). Success for them was about strength of character, persistence and an unwillingness to give up, making repeated attempts to reach their goal. They perceived themselves as justifiable winners who, in surviving a long ordeal, had eventually got the prize that they deserved: 'After having various surgeries to explore unexplained infertility we kept being told to come back in three months, then 9 months, despite us voicing concerns over my age as by this time I was approaching 36. We asked for referral to a fertility unit and even though this was agreed there was some reluctance by the consultant. We then had problems in getting an appointment as the unit claimed they hadn't received my medical records. We ended up chasing both hospitals and it was over 6 months before we finally got an appointment. Once we were seen, then things started moving. Our second attempt was successful, resulting in the birth of our twins, so for us fertility treatment was worthwhile'.

For others, the treatment process, and waiting and distress were framed as 'a price' to be paid to achieve their goal, and the emotional and financial costs were 'worth it'. However, in an area where costs can be substantial, the resulting children are at the same time seen as 'a gift beyond price': 'My experience was well worth going through as on the second treatment I got pregnant and we have a wonderful daughter who is the life and soul of our lives', 'For individual families the gift of a child that you thought you'd never have is priceless', 'No-one can put a price on the perfect and beautiful daughter we have', 'I cannot put a price on having a baby ... I consider myself enormously privileged to have these children. Money does not come into it'.

In answering the question about how treatment affected their lives, many women responded by first positioning themselves and then providing personal accounts of treatment. Infertility was framed as 'having difficulty in doing what so many other people do so easily' and by inference, without even thinking:

'People who are desperate for a child and cannot afford to pay for treatment should receive it free. Enough of tax-payers' money is given to parents who live off state benefit and keep having children, even though they can't afford to keep themselves'. Some described the way in which infertility and the need for treatment had coloured their lives, seeing themselves as 'unlucky' and not being able to have children as 'unfair': 'Luckily we didn't have to go too deeply into the fertility process, but even for us we felt a bit freakish. There was very little support – clinical explanations, but not enough information.When you're desperate for children every month seems like an eternity ... It worked for us – we were lucky'; 'How unfair it is that I would have had to have waited 3 years for IVF treatment because I already had children.... But my husband who had no children of his own didn't matter.... Surely he was entitled to have children of his own every much as a woman is'.

Choice and control in the treatment process

'Going through treatment is like going into a dark tunnel. You have no idea where you are going or how long it will take and once it commences it is all consuming and you have to keep going'. In this evocative description that encapsulates uncertainty, longing and submission to the process, there is the clear idea of setting out on a journey. For some women, the trajectory they followed was more of an obstacle race in which they were beset by unexpected hurdles and the sequential narratives from diagnosis, through different treatments to the birth of one or more baby and their present position, support this view. Both accounts reflect the lack of certainty and difficulties of the treatment process, at the same time the intended destination or goal which was held in mind.

The lack of choice in relation to their own infertility and of control in relation to the type and timing of treatment was evident, with many women feeling frustrated by the whole process and the specific elements with which they were obliged to comply. They described the process of undergoing treatment: difficulties with diagnosis, experiencing a range of tests and types of treatment, repeated treatments, the use of medication and its administration and pregnancies that failed. Once committed, the obligations were multiple: having 'investigations', 'taking samples in', 'ovulation testing', 'injections and blood tests', 'trips to clinic to check follicle growth', 'laparoscopy' and 'surgery'. One woman described these very succinctly: 'Every month (for 6 months) – Clomid tablets for 5/6 days, HCG injection on day 12, blood test on day 13/14, sex to order!!'. Some referred to physical symptoms arising from the treatment: 'I felt very sick and tired with the tablets' whereas others described an 'uncomfortable feeling as eggs mature' and 'pain from egg removal'. Others wrote about their efforts to carry on 'as normal whilst feeling unwell during treatment', appearing fine on the surface, beneath which emotions were held in check.

The emphasis for many women was on the mechanics, the events and obligations that follow once treatment has been agreed, the taking of samples, sperm counts, checks on ovulation and oocyte development, doing the right thing at the right moment for biology and thus the best chance of success. Many emphasized their lack of control and the expectations and

requirements associated with treatment. Planning was key to managing these, especially in being able to take time off or away from work. Women's attitudes differed as shown by the language used, perhaps as a function of the type and duration of infertility problem and different treatment regimens. Many described reorganizing their day to try and maintain a normal life while receiving treatment. Minimizing the impact on work required juggling: some made 'early morning appointments for monitoring', and one, a teacher 'tried to fit appointments into' free periods' or at the end of the day'. Distance made a difference and some felt 'very lucky in having easy access to clinics' and 'fortunate in having a very flexible job working from home'. Others felt conflicted by the parallel demands of medical treatment and their working lives: 'Because of the timed injections and inseminations it could be difficult getting from work'. 'It was very difficult to plan work schedules as I couldn't exactly predict which days I would have off. My annual leave all went on fertility trips, so little time was left over for holidays'.

Emotional and physical pain

The difficulties associated with conception resulted in many women describing themselves as becoming 'totally preoccupied', with 'an all-consuming need', experiencing great distress and 'feeling you will never become a parent', 'There is so much stress and distress when one wants a baby and is unable to conceive – it becomes all encompassing'; 'All the fertility tests were conducted in the antenatal clinic! Seeing posters of babies and being surrounded by pregnant women caused a lot of unnecessary distress.... When we were told I couldn't conceive naturally and we were told to go for IVF, it was very quick and cold... No counselling was offered. It was very cold and routine, but to us it was devastating news'.

Many women, like this one, described themselves and their partner as being 'devastated' by the diagnosis and the problems they encountered in gaining access to treatment. The use of this kind of language invokes images of disintegration, of falling to bits or being demolished in the face of this kind of adversity. Adopting a deficit model many women implicitly took up a position in which motherhood and becoming a parent is accepted as the norm, the achievement of which is seen as becoming 'complete'. The reparative nature of the pregnancy and successful birth cannot be understated as far as many of the respondents were concerned: 'I never thought I would be a Mummy, but now I have 2 year old twin girls', 'My husband and I love watching our daughter develop, it has made our family whole'; 'The house is alive now, whereas before it wasn't. I feel our family is now completed'; 'The desire for a child is overwhelming and even unbearable at times, but the fact that you can go through what seems like hell and come out the other side with the thing you wanted most is remarkable'.

A major theme which emerged from many women's responses concerning the impact of the treatment process, though not explicit in the women's words, relates to the tension between the way that the women's bodies were treated in what was an artificial process and being helped to achieve a natural outcome. Treatments were described as 'painful', 'tiring',

'exhausting', 'stressful', 'hard and almost physically unbearable' and 'associated with dramatic mood swings'. Different intensities of feeling and response are shown in the choice of terms that women used and some even described themselves as feeling 'bruised', 'damaged' and 'hurt' by the treatment process. 'The treatment is physically very hard and almost emotionally unbearable—I have decided that I cannot bear the idea of ever doing it again as the failure and disappointment is devastating and the only thing that has kept me going is my child from the first successful IVF. There is also huge sadness that she will be an only child and never have the chance of being part of a family properly, and guilt that if anything happens to us she will be alone'.

In many accounts, the impact of experiencing infertility and of treatment on both their psychological and physical well-being were evident to the women themselves. Many wrote about the physical and emotional effects of treatment, often at the same time. Treatment was seen as 'not so much a physical as a mental strain'. They emphasized the psychological consequences: their 'emotional pain', that the process of treatment was 'emotionally and financially crippling', 'emotionally stressful' and 'emotionally draining' from their perspective: 'My fertility treatment was a long and emotionally bruising experience. To have my son I gave up a successful career. I am still not fully recovered (emotionally) from the experience. You deal with each failure and knock-back, but there is a cumulative element that gradually takes its toll'.

In describing how treatment had affected their lives, some women also mentioned the impact on those close to them, including their partner: 'It tests people's relationships to the limit'; 'My new husband and I talked of starting a new family before we were married and we went through a terrible time because I felt awful I couldn't give him a child I just took it for granted I could ... this could have caused the break-up of our marriage'. There was also an awareness of the process by which a normally private activity results in comment, approval or disapproval, depending upon the circumstances, and the way in which this aspect of their lives had become public. Some women were concerned by how they thought others saw them, finding it hard to protect themselves and to manage their other close family members' concerns. In this and the wider societal context, they were aware of the expectations and judgements that can be made about those experiencing fertility problems, some of which focused on older mothers, single parents or single sex couples receiving treatment.

Being a person

Although the process of treatment might seem ordered and mechanical, the context for most women and their partners was an emotionally charged one, in which routine care and the associated procedures could be experienced as reductive. For some women, the whole process was without dignity, 'dehumanizing', they 'felt like a freak' and would like to have been 'treated more like an intelligent human being'. One woman described her stark experience: 'When receiving DI I was placed in what was being used as a storage room, where I lay on a bed. They did what they did and told me to leave after half

an hour. I went through this six times and each time I felt very upset. Not only was I looking at a load of stacked and dusty furniture, but no-one came to check that I was alright afterwards'. Another wrote 'When I was told by my consultant at the NHS that I was infertile and nothing could be done for me due to my age (38), I was asked to leave the room more or less immediately—to make room for the next patient. Of course I was very, very upset and in floods of tears. I feel you should be given counselling or at least a room in which to compose yourself after being given such devastating news. The whole experience of that day will haunt me for ever'. The lack of social contact in the first account and, in addition, privacy in the second emphasizes the felt absence of dignity and respect, contributing to feelings of isolation and separateness.

The theme that runs through the terms the women used to describe their experience and the longer quotations is depersonalization, an element of which is feeling separate, outside the group, not human, sometimes reduced to the body parts associated with reproduction. Another element involves a lack of autonomy, being dependent on and controlled by others and the situation in which they find themselves, with little choice about what they feel they must go through. Their lives were dominated by the treatment schedule which 'takes over everything you do', turning life into an 'emotional rollercoaster', 'The whole process of IVF/IUI is extremely invasive and takes over your life'. The perception of being taken over and having no control was common: women and their partners had 'lives which revolved around treatment'.

Stoicism and sacrifice

For other women, in contrast, having to jump through hoops and being prepared to do almost anything to have a baby suggests a deliberate choice made with commitment and determination. Thus for some, there was stoicism in the face of what seemed like setbacks and a sense of putting up with the inconvenience, discomfort and pain. Some responses to the question about the impact of treatment on their lives were very practical and matter of fact, with women writing less about distress and more about getting through the process: 'The main inconvenience was to keep going for scans, but I was so desperate to get pregnant that I didn't mind too much'; 'Bit of a pain getting time off and getting there and back'; 'The process was simple and the only frustration was waiting'; 'IVF was not disruptive, more stressful waiting for different stages in the cycle'.

In some accounts there was now, in the context of success, a sense of weighing in the balance the requirements of treatment against the hoped for and now known outcome. Thus for them, the balance was in favour of sacrifice and they saw the treatment process, physically and psychologically, as a price to be paid: 'I wanted the baby so much I didn't care'. 'Although it was the most demanding, terrifying time of my life I would do it again and indeed start it all again next week'. The main focus of concentration was on the treatment itself – 'it was something we had to do'. Some felt that people in their position should accept the disruption to their lives and that it 'should not matter', with the inference that if this is what you have to do, that is how it is.

Accounts of numbers and measurement

In the course of fertility treatment, as in many other areas of health care, patients acquire and use the medical vocabulary associated with their condition and clinical management. In addition to being able to communicate with the health professionals using their terms, this reflects a need for mastery and coping (Marks *et al.*, 2000). It is also a function of the way that information about their situation and treatment is presented to them. Thus the language used and women's stories were often constructed with reference to number, measurement and time. Number was pervasive in terms of a woman's age, the number of years or months the couple had spent trying, the odds and chances of success, the numbers of attempts, of treatments allowed, costs in terms of money, days off work, and distance and numbers of embryos and children. The idea of measurement was closely linked with the concept of number and was evident in references made to cycle length and fertile periods, levels of reproductive hormones, medication doses and levels and size of follicles.

Time was a linked theme, not always framed in quantifiable terms. Women implicitly referred to the passing of time, elapsed and wasted time, the shrinking time window for medical intervention and the need for clock and calendar watching: 'waiting for appointments'; 'waiting for treatment'; 'waiting for different stages of the cycle'; 'hormone injections I had to give at certain times'; 'It took most of the day to go back and forth and sometimes you had to go several times a week'; 'The whole process is difficult logistically, having to arrange time off at short notice due to your cycle and travelling so far'; 'You had to go to the clinic at certain times (precise times) to be screened no matter what else you were doing'; 'My treatment took six years from start to finish'. The units in which time was measured ranged from hours and days to years, depending on which aspect of the treatment experience a woman was describing, often alternating between detailed aspects of treatment and the larger issue of coping with uncertainty. The accounts place time and biology together, with women feeling at the mercy of biological processes, specifically the ageing process, their menstrual cycles and timing of ovulation and, by implication, the timing of sexual intercourse.

Differences in care

Approximately half the respondents indicated that there were no ways in which their experience might have been improved. Among these were some who described their care very positively: 'Everything was dealt with wonderfully, all advice and treatment was first-class'; 'Staff were wonderful and treatment worked first time'; 'The treatment and care we received were wonderful. The staff were both professional and compassionate'; 'Excellent experience at hospital. First two GP appointments were a lesson in sex education'. There were also others who were aware of the limitations of the system and thus saw no possibility of improvement. Many of those who identified improvements that could be made used both positive and negative terms. Health professionals were generally perceived as having an 'understanding', 'friendly', 'caring', 'helpful' and 'supportive' attitude. However, the treatment from some was experienced as 'impersonal', women could feel 'intimidated'

and 'misunderstood' and spoken to in a way that was 'dismissive', 'unfriendly' and 'insensitive.' Women wanted care 'to be less impersonal' and not 'always different consultants and nurses'. For some, the tone of voice was the focus, with clinicians particularly being seen as taking a tough line, and delivering a message that was 'hard' to hear. Although there was considerable appreciation of the skill and expertise used in answering their need for help, they were not necessarily treated with respect and sensitivity.

The quality of communication and the type of information provided by staff were an issue for some women. Although some were given sufficient and appropriate information: 'The third and successful treatment was so different. The staff seemed to care and encouraged my husband to be part of and carry out injections. At every stage of the process I was kept informed of what was going to happen and how I might feel'. Others felt improvements were needed 'More specific information from GP about most fertile times in your cycle and how to identify these', 'I got more information from www.gettingpregnant.com than the GP', 'Not having to see different doctors and having to tell my story over and over', 'Better communication, I needed to be told what was happening and why'; The first fertility unit we that attended didn't explain very much and we were treated like a number, rather than people'. Some expressed a specific need for support of a psychosocial nature: 'Better counselling when treatment doesn't work', 'Some follow-up/counselling would have put things into context'. A particular concern for some women was that their previous history was not known to the health professionals caring for them, with little continuity between appointments or time to read notes. That some had experienced miscarriages and thus this was not a first pregnancy or that this may not originally have been a singleton pregnancy mattered very much to the women concerned and affected the assumptions made and the way they felt they were treated.

Care provision and the financial and emotional costs

When asked about how care could be improved, women described what had happened to them with the inference that this should not have been the case, or else made overt suggestions. The latter were grouped by topic and the proportions shown in rank order are based on the 155 suggestions made by 110 respondents (Table III). With those who were critical, the issues of choice and continuity arose and how the health care system did or did not address their needs. However, for this group of respondents, the areas of greatest concern were with time and cost. Delay at any one of a number of stages was a key issue: in recognition of the problem and diagnosis, the time interval between diagnosis and initiation of treatment and then between appointments and treatments. Frustration with the system, with the requirements of treatment regimes, the way in which they felt forced to seek care out of their immediate area, sometimes in the private sector, joined with an awareness of the decreasing amount of reproductive time available for them to achieve their goal, was evident in individual responses.

Anger and distress about costs and payment made for drugs and treatment were expressed by some women who were upset

Table III. Topics relating to improvements in infertility treatment

Aspects of fertility treatment which could have been improved	Number of responses (%)
Reduction in referral time, waiting for appointments and investigations	39 (25.2)
Financial help with treatment	27 (17.4)
Access to care locally	19 (12.3)
Better support and counselling	18 (11.6)
Differences in the attitude of health professionals	14 (9.0)
Better information	6 (3.9)
Less contrast in care between facilities and National Health Service and private care	7 (4.5)
Greater continuity of care	6 (3.9)
More choice relating to clinic appointments	3 (1.9)
Better inter-professional communication	3 (1.9)
Other, for example, not having clinic next to maternity wing, greater awareness of complementary health care	13 (8.4)
Total	155 (100)

about the adverse impact this had had on their financial circumstances and well-being and their ability to seek treatment to have another child. The part that geography and location played was also a significant one for some, in relation to where treatment was received and how that treatment was organized. The personal, economic and emotional costs referred to by many, of travelling considerable distances, fitting work and sometimes childcare around treatment and the sense of unfairness about where and what kind of treatment was provided, found echoes in the improvements suggested. These relate to access, continuity, timing and what were perceived as delays, and costs: 'Easier and better access to medical advice'; 'Treatment in the one hospital'; 'Shorter wait for initial consultation'; 'Shorter waiting lists for NHS treatment and fewer hours spent in hospital waiting rooms'; 'A clinic before or after working hours'; 'Less time waiting for scans and blood tests'; 'Shorter waiting list for tubal surgery'; 'More affordable treatment needs to be available more widely'; 'It would have been nice to have all the drugs free' and 'The NHS could have paid in part'.

Women often provided a narrative, contrasting experiences in different hospitals or clinics: 'The first fertility unit that we attended didn't explain very much and we were treated like a number rather than people. They were always rushed and I even had to sign the consent for egg collection in the corridor on the way in to theatre, but the next fertility unit and staff were excellent'; 'I had 3 treatments of ivf – one in ... was private but very impersonal and I feel this was because we were one of so many couples with not enough time to give to all. The second and third treatments were at ... I had a great experience and the staff were able to give individual attention at all times – even by telephone if needed.'

Work was an issue for many women and their partners. Although some referred to 'very understanding' employers, other women described the conflict between treatment and work: 'My boss was not very sympathetic'; 'Work did not understand'; 'Organizing time off work and work around menstrual cycles was very difficult', 'I had to work my shifts around the tests'. Some minded about the lack of privacy associated with the personal issue of infertility: 'I was uncomfortable having to explain to my manager why I required time off'; 'It was difficult having to tell my employer and to fit appointments in around work'. Loss of pay and leave spent on treatment

mirrored for some women the wider lack of recognition of the difficulties associated with trying to overcome problems of infertility. For these two couples, the financial costs of treatment were considerable, even punitive and continue to affect their lives: 'We are both self-employed and were reliant on ongoing contracts for income. Not only did we both lose all income on the days that we attended clinics but we also lost the goodwill of those to whom we contracted.... We are still trying to rebuild our business. The total cost cannot be calculated but I would estimate the loss of earnings to be in excess of £20000. No assistance was available for self-employed people at any level. We were refused both tax credit and benefits during treatment and maternity leave'; 'We waited to have children until we were sure we could afford to look after them but by waiting we were told we were not allowed any help with treatment. We only got help with the first lot of drugs because of my G.P's embarrassment at not being able to help me...they changed the rules on that while I was waiting to see if I was pregnant.... I have since tried for a 2nd child and now feel sad and resentful that we have no savings left at all and my husband had to work 80 hours a week while we had a new baby to save up for a chance of a sibling and that did not work'.

Fairness and equity

The responses of the women who wished to tell policy makers in the NHS or government about their experience of infertility treatment were grouped by topic and the proportions shown in rank order (Table IV). Half the women (114) did not respond or did so with responses not relevant to policy. The totals shown are based on the 183 suggestions made by 116 respondents.

Equity and cost were the dominating issues, although there was recognition of resource issues and of the need for clarity with regard to policy. Although many women wanted to let policy makers know that they had been treated well, others had messages to pass on: 'We were a very lucky couple who were in a position financially to fund the treatment – What about those who desperately want children, but can't afford the charges?'; 'We were in our late thirties, got no help and had to pay all costs'; 'We are so grateful to have received fertility treatment on the NHS because we couldn't afford to go private'; 'The cost of treatment caused a lot of hardship and

Table IV. Topics relating to infertility treatment policy

Views of respondents who received infertility treatment	Number of responses (%)
Would like to see free treatment on the National Health Service	34 (18.6)
Equal access throughout the country, no 'postcode lottery'	31 (16.9)
High financial costs involved in treatment of some couples needs review	29 (15.8)
Current unfairness and inequity needs to be addressed	21 (11.5)
Faster treatment on the National Health Service is needed	14 (7.7)
Better understanding by policy makers of the life-changing nature of this type of treatment	10 (5.5)
National policy required on treatment	9 (4.9)
Review of cut-offs for age, previous children etc.	9 (4.9)
National Health Service part-funding should be provided	5 (2.7)
Increase resources for infertility treatment nationally	7 (3.8)
Review drug budgets and general practitioner prescribing	4 (2.2)
More specialist help is needed	4 (2.2)
Review of current limits on numbers of, for example, IVF attempts allowed for each woman	3 (1.6)
Make funding system and entitlements clear to all health professionals involved	1 (0.6)
More public debate on the issue of infertility treatment	1 (0.6)
Women/couples should pay for treatment	1 (0.6)
Total	183 (100)

stress'; 'I was very concerned about finding the money if it was going to be necessary for IVF'; 'Thanks to the NHS I have a beautiful daughter ... when I wished to become a Mum I needed help. Fertility treatment on the NHS is valuable and very worthwhile as it gives everybody the chance to become parents'.

There was awareness and concern about inequity in terms of who was able to obtain NHS treatment and of the effects of geography and location on access. Advice to policy makers in the women's own words included: 'Do not make this treatment unavailable due to money issues'; 'Everyone should be treated equally across the country'; 'Make it fair, standardise'. There were also pleas for increased funding and faster access to treatment: 'Infertility is sufficiently distressing and has such a major impact on one's life that it should get more of a priority in funding'; 'There should be an increase in funding ... we were lucky enough to be able to spend £10,000, but for many this is impossible'; 'Don't make us wait as long before any treatment can be obtained'; 'Continue to make it available on the NHS without long waiting lists'.

Inequity in access to the resource of fertility treatment concerned many who referred to an 'unfair post-code lottery', treatment which 'should be more readily available on the NHS for lower income families' and the need to review cut-off points for NHS treatment: 'Unfair that different health authorities have different policies and waiting times. You can receive fertility treatment in some areas and not others'; 'The NHS could provide a better service. This is stressful enough without worrying about costs and money'; 'There was a question of which health authority should pay for IVF due to my post-code'; 'We were penalized for having nothing physically wrong'. Women also felt punished because they had waited their turn and though they now had one child, the prospects were poor for having a sibling for the child born after fertility treatment. It is not surprising that the linked issues of equity and costs should be so evident among these responses. As mentioned earlier, a considerable proportion of women had obtained some or all of their fertility treatment in the private

sector. More than three quarters of these women had received IVF, sometimes in addition to other forms of treatment, and the costs for them and their partners were often considerable. However, equity was also of concern in relation to access and availability, and this was voiced by both those who were living in the right location and those who felt they had been lucky in having sufficient resources to pay.

Table V summarizes the key concerns and wishes of women, with examples in their own words.

Discussion

This research provided an opportunity to explore the views of women who had been successfully treated for infertility. The way that medical care was managed, the clinical treatment hurdles and processes, healthcare organization barriers and constraints, all reinforced the lack of choice and control that they experienced in relation to their own reproduction. There were competing metaphors in the language used. Throughout many of the accounts, a gambling metaphor, often in the form of a 'lottery', was in operation, with the implicit possibility of being a winner or a loser (De Lacey, 2002).

It is of interest that even with a group of women who had achieved their goal of pregnancy and the birth of a child, critical views were expressed about specific aspects of care and of what they saw as the fundamental issue of fairness and inequity associated with the treatment process. Perhaps what may be of concern is that even after successful pregnancies and the time that had passed, some women who received treatment for infertility maintain a view of themselves as wounded by the process and have still to come to terms with the intense distress experienced at that time. It has been argued that monitoring the needs of all couples undergoing infertility treatment should be an integral part of routine care and that those who experience higher levels of psychological distress may need some continuing care and follow-up, whether or not a successful pregnancy ensued (Slade *et al.*, 1997; Peddie *et al.*, 2005).

Table V. Women's wishes relating to fertility treatment

	What women wanted
Respect and compassion	'Treatment that counts us as human'
Information	'First two GP appointments were a lesson in sex education!'
Effective communication	'After having a laparoscopy I had to wait 10 weeks before being told my results'
Equity	'Without free NHS treatment I would not have my daughter. We would never have been able to afford private treatment'
	'There is age discrimination in the process and as we were in our late thirties we got no help and had to pay all costs'
Access	'To have treatment locally'
	Every area of the country should operate the same policy on treatment. On the NHS it is a postcode-lottery
	'They had numerous research studies and because we were desperate and didn't have much money, we were keen to volunteer'
Continuity	'One set of medical staff rather than someone different each visit'
Adequate follow-up and support	'A better after-care service'
	'Talking to someone who has been through the experience'

In retrospect, for many women in the study, there is a sense of being complete and the role of parent and being part of a family are highly valued. Yet some are still carrying the burden of resentment and regret about the need for treatment and the kind of treatment received. Inequity still hurts, though it is balanced by very positive feelings when reflecting on the child or children they now have. They were 'lucky' and 'fortunate' to have lived in the right place, found the skilled and knowledgeable care required and had the resources to pay for some or all of the treatment. The life-changing nature of the experience of infertility, having treatment and overcoming this obstacle to normal life was widely acknowledged. A sense of triumph and satisfaction was experienced, and gratefulness to those involved, though for some, anger that things could have gone better or been managed more effectively, was still present.

In undertaking this qualitative analysis, the aim was to better understand the perspective of women who have experienced treatment for infertility and to identify some of their psychological and practical needs. The insights provided by the women themselves, although limited to those who had successful treatment, may help those managing and planning the service in this area of health care to appreciate the issues from the user perspective. The quality of care experienced seemed critical in framing the perceptions of many women. That the staff took care, showed understanding, kindness and respect was associated with women feeling human and expressing a positive view of the treatment process. Those who did not feel cared for in this way argued for a less-clinical and more compassionate approach, with greater appreciation of an individual's history and experience.

In relation to policy, the women emphasized the need for acceptance by others, including health professionals, of the medical nature of the problem and for their position to be understood—not simply seeing the issue as one of a woman or couple being unable to adjust to childlessness. They also argued for acceptance that everyone in these circumstances has a right to treatment. The recent changes in UK policy address some of the points raised (National Institute for Clinical Excellence, 2004), although the extent to which the guideline has been adopted is not yet clear.

The limitations of this part of the MCS study arise mainly from the use of postal questionnaires, resulting in not being able to probe particular issues in the way that is possible using an interview methodology. However, although some researchers have argued that analysis of open-ended responses to written questionnaires is not conventional qualitative research material (Pope and Campbell, 2001), others have used such responses in exploring similarly sensitive issues (Turner and Coyle, 2000) and argue that such data may highlight issues missed by structured question formats (Garcia *et al.*, 2004; O'Cathain and Thomas, 2004). The benefit has been that it was possible to look at the views of a relatively large number of women whose children and families are part of a cohort that will be followed up over a long period of time (Dex and Joshi, 2005). Certainly much larger numbers were included than would be possible using an interview approach.

Health professionals working in the area of fertility treatment may find the results very familiar, but it is important to view the experience of treatment from the perspective of those undergoing the healthcare interventions they provide. When treatment is structured in a way that seemed automatic and staff do not seem to respond to women as individuals, this contributes to feelings of isolation and depersonalization. In taking on a problem-solving approach, as many clinicians essentially do, less emphasis is placed on individual perceptions and attitudes. This qualitative analysis allows the perspective of those most involved to be understood on their own terms.

Conclusion

Infertility is an issue that goes to the core of the individual. How women chose to respond to the questions asked and the language they used reflected their individual experiences. Reading their accounts and appreciating the diverse ways in which perceptions of their experience are articulated has led to a complex picture in which physical and practical aspects of the clinical treatment are interwoven with emotional responses. The message that the respondents wished to convey to health professionals and other women and couples considering treatment for infertility was very clear. Such treatment is not an

easy option: 'This is an emotionally and physically difficult process' and with every failure the feelings of never becoming a parent are re-visited, even after success. From the outside, it is easy to expect these women for whom treatment has been successful to be grateful and to move on. Yet, as shown in the quotations chosen, particularly those relating to stoicism and emotional pain, the experience of treatment has marked them, apparently making some tougher and more resilient and others more vulnerable. Among almost all, there was a desire for improvements in this aspect of health care that address the needs of the individual, both in relation to the psychological impact of the problem and of the treatment process.

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