

A qualitative study of women's decision-making at the end of IVF treatment

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BACKGROUND: The decision not to pursue further *in vitro* fertilization (IVF) after one or more unsuccessful attempts is an important and often difficult one for couples. Relatively little is known about the woman's perception of this decision-making process. The aim of this study was to examine patients' perspectives of decision-making, including circumstances influencing it and satisfaction with the decision-making process. **METHODS:** Semi-structured interviews were conducted with a purposive sample of 25 women who had decided to end treatment after unsuccessful IVF treatment. Interviews were tape-recorded and transcribed by means of thematic analysis using the open coding technique. **RESULTS:** Women experienced difficulty in accepting that their infertility would remain unresolved. Many felt that they had started with unrealistic expectations of treatment success and felt vulnerable to the pressures of both the media and society. Although the decision to end treatment was difficult, it offered many women a way out of the emotional distress caused by IVF; however, the process of decision-making created a sense of 'confrontation' for the women in which they had to address issues they had previously avoided. Adoptive parents perceived less societal pressure than those who remained childless. **CONCLUSIONS:** Efforts to improve the psychological preparation of couples who decide to end IVF treatment should be directed towards examination of the existing system of consultation, which has certain limitations in terms of the quality of communication and the provision of post-treatment support. Further efforts to develop strategies, which facilitate the decision-making process, should be considered.

Key words: decision-making/ending treatment/*in vitro* fertilization/perceptions

Introduction

Although the prevalence of infertility has remained relatively stable since 1965 (Keye, 1999), the availability of medical services, media attention and public awareness of infertility treatments have increased dramatically (Burns and Covington, 1999). Many couples embarking on an *in vitro* fertilization (IVF) programme are optimistic with unrealistically high expectations (Beaurepaire *et al.*, 1994; Slade *et al.*, 1997; Eugster and Vingerhoets, 1999; Hammarberg *et al.*, 2001). IVF and intra-cytoplasmic sperm injection (ICSI) yield only a 20–25% chance of a live birth per cycle; thus many leave the IVF clinic childless. The long-term emotional impact of IVF treatment and the role of social and psychological factors that influence women to continue or stop IVF have been studied in previously published work (Van Balen and Trimbos-Kemper, 1993; Leiblum, 1997; Callan *et al.*, 1988; Boivin *et al.*, 1999; Hammarberg *et al.*, 2001).

Patient decision-making is an increasingly important area of research (Holmes-Rovner *et al.*, 1996; Guadagnoli and Ward, 1998; Edwards *et al.*, 2003), and shared decision-making is seen as a mechanism to decrease the informational and

power asymmetry between doctors and patients (Eddy, 1990; Emanuel and Emanuel, 1992; Ryan, 1992). Shared decision-making has been advocated as an ideal model in the medical encounter (Brock and Wartman, 1990; Gray *et al.*, 1990; Deber, 1994), and although the concept has been poorly defined, there has been a recent shift towards informed choice rather than merely informed consent (O'Connor, 1995).

The purpose of this study was to examine the circumstances surrounding the decision-making process (as perceived by the respondents) at the end of unsuccessful IVF treatment, including women's views on the quality of care and level of communication received from the IVF clinic staff.

Methods

The authors had previously conducted a quantitative-questionnaire based study on women who had decided to end treatment following failed IVF (with no embryos remaining in storage) between 1999 and 2001 (Peddie *et al.*, 2004). In all cases, the plan to end

treatment had been documented in the case notes following a final consultation with a clinic doctor and none of the women were registered for further IVF treatment. The minimum and maximum period of time since stopping treatment was 3 and 24 months, respectively. None of the couples had any children born as a result of IVF treatment. Two women had subsequently adopted one child and another a sibling family of three.

A letter of invitation, an information sheet and a questionnaire were sent to each woman. Women could choose to participate in one or both parts to the study: (i) completion of questionnaire only, and (ii) completion of questionnaire and consent to interview. Those who did not wish to participate or have further contact could opt out by returning the tear off slip. The questionnaire-based study aimed to assess women's perception of the decision to end IVF and measured satisfaction with the decision-making process as well as the decision made (Peddie *et al.*, 2004).

The present study used qualitative methods to explore women's experiences of the circumstances of the decision-making process in more detail. Out of a total of 71 women who completed a postal questionnaire, 68 (96%) agreed to be interviewed. The authors used purposive sampling in order to include a sub-set of 25 women (selected on the basis of questionnaire responses) with a wide range of demographic characteristics and classifications of infertility. Details available from Medical Records revealed no differences between responders and non-responders. Approval for the study was obtained from the Regional Research Ethics Committee.

Interviews were conducted by a research midwife (V.P.) and lasted ~40 min. Except for two interviews which were conducted in the patients' own home (at their request), all were undertaken in a designated non-clinical room within the IVF Unit. Interviews were tape recorded and transcribed verbatim. The interviewer (V.P.) was known to some of the women as she had input into their clinical care in the past. We initially sought to interpret the woman's experience (in her own words) which led to the final decision to end IVF treatment. We then explored their reasons for selecting particular responses (in particular, 'neutral'), to several questions in the questionnaire. Thematic analysis and coding of the transcripts was performed by V.P. and checked against those of a second researcher (E.v.T.) to reduce inherent bias. We amalgamated several themes; for example, one woman commented that she felt 'so low' after failed treatment, and another attended her GP for anti-depressants as a result of failed treatment. These were grouped together under the heading 'Stress associated with IVF'. The authors acknowledge that there is a degree of overlap, and that certain issues are common to two or more themes. Interview extracts have been identified with quotation marks and the respondents identified by a code number, and in the majority of cases, they denote the woman's perception of various aspects of the decision-making process to end treatment, which were made 'as a couple'.

Results

Demographic details of the 25 respondents are shown in Table I. Twelve (48%) had experienced previous pregnancies, although none had had a live birth. More than half had a university/professional qualification. The qualitative analysis identified ten overall meta-themes as most descriptive of the phenomenological experiences (Daniluk, 2001) of the respondents which impacted on their final decision to end treatment: difficulty with acceptance of infertility; stress associated with IVF; unrealistic expectations of treatment; pressure from media and society; insufficient information

Table I. Demographic profile and sampling frame for this study

Details of women in study (From sub-set of 71)	<i>n</i> = 25	
Mean (SD) age of women (years)	37	(4.5)
Mean (SD) duration of infertility (months)	35	(12.3)
Mean (SD) fresh IVF cycles	3.2	(1.2)
Mean (SD) frozen-thawed embryo replacements	1.7	(1.5)
Cause of infertility		
Male factor	8	32%
Tubal factor	5	20%
Unexplained	8	32%
Endometriosis	3	12%
Premature ovarian failure	1	4%
Maximum educational qualifications:		
O levels	7	28%
A levels	3	12%
Diplomas and other professional qualifications	8	32%
University degree	6	24%
No recognized academic qualification	1	4%

Table II. Common themes from analysis of interviews

Themes
Difficulty with acceptance of infertility
Stress associated with IVF
Unrealistic expectations of treatment
Pressure from media and society
Insufficient information specific to the individual
Social and professional opportunity costs
Physical and emotional pressure exerted on the couples' relationship
Information provision and communication skills
Lack of continued support from the IVF unit

specific to the individual; social and professional opportunity costs; physical and emotional pressure exerted on the couples' relationship; information provision and communication skills of the doctor during the final consultation and the lack of continued support from the IVF Unit (Table II).

Difficulty with acceptance of infertility

For many women, the point of acceptance of childlessness had not been reached, which hindered the decision-making process. 'I am always going to have regrets that we can't have a child, but you have to accept what you have got rather than what you haven't. You have to make alternative plans and they don't include children' (043). However, for some, 'many questions remain unanswered' (024), and 'many issues unresolved' (023). Similar sentiments were voiced by others: 'Facing up to the fact that you will never have your own child is very traumatic and in a sense we feel forced into the situation of being childless' (100), or: 'I think it's still happening [acceptance], it's such a long process, I mean we stopped treatment in May of last year, and I still can't accept it' (028). Although the decision to end treatment had been made, these women were generally less positive, not only with their inability to accept biological childlessness, but of their decision. Those who went on to adopt or have less invasive treatment such as donor insemination were more likely to feel more positive about their future, and no longer viewed themselves as 'childless': 'I must admit the adoption changed things for us dramatically. We had another focus and we

were probably ready to move on earlier than those couples for whom adoption is not an option' (042). One woman was more cautious about adoption and viewed the process as socially less acceptable; 'We were too old for adoption, and anyway, we were not prepared to take on a child who may well be psychologically damaged' (043).

Stress associated with IVF

A common response from women was related to the stress caused by IVF treatment, and the process of decision-making often exacerbated this. However, relief of the cyclical process of 'treatment and stress' was evident once the final decision to end treatment was made. One interviewee (008) indicated that: 'the IVF for me was an extremely traumatic experience and I just wanted it all to end' (008), and went on to clarify that it was her life that she wanted to end. Others reported similar feelings of depression: 'The GP started me on anti-depressants. I just wasn't coping with it all' (028), or: 'In a way, I felt quite depressed, not in the clinical sense, but I felt so low, so down, in a way I had never felt before. That lasted for about two months and I decided then that I never wanted to feel like that again' (043).

Unrealistic expectations of treatment

Making the final decision to end treatment was influenced by unrealistic expectations of success and the inability to cope with treatment failure: 'I suppose we were naïve in thinking that IVF would work first time' (011). Many women were initially hopeful, but eventually succumbed to despair after repeated unsuccessful cycles of IVF: 'In the beginning there was so much hope, I mean it was something positive we could do, and now ... there's no purpose in life anymore, no relationship left. What's the point?' (139). Many felt that continuing treatment was their only means of suppressing feelings of negativity and pessimism. Some remarked that their optimism had been borne out by medical staff explanations for lack of success, which appeared to have been withheld until the very end: 'If we had been told earlier about the possible genetic condition, then we would have been able to make a positive decision to stop treatment earlier' (116). Respondents appeared to go through a period of critical self-reflection in arriving at the decision to end treatment: 'We never thought we would still be here [having IVF] three years on, but in time your attitudes change and you are faced with dilemmas you never thought possible' (018).

Pressure from media and society

Many women had discussed ending treatment with family and close friends, however, they did not influence them in making the final decision. Others were desperate for additional information, which offered them a way out of the vicious cycle of treatment, failure and despair. Prior to making the final decision to end treatment, many women had searched the Internet for information about the possibility of new treatment options: 'I searched every web-site you could imagine. If anything, it made me feel better about my decision in that thousands of people were going through the

same experience' (079). However, some felt that medical staff appeared uncomfortable when faced with the results of their own literature search: 'You never seemed to approve of the information we downloaded from the Internet, but we had to explore all options before making the final decision, leaving nothing undone I suppose' (147). In essence, the media proved to be another source of pressure on couples who experienced a social obligation to try new technology in order to reproduce: 'It's the whole extended family thing. It's almost like a fashion accessory—sorry to be so flippant, but you're not accepted in the same circles or the same way if you don't have kids' (086). One couple commented on the apparent effect of 'monthly media headlines' that created indecision with regards ending treatment by suggesting that significant breakthroughs were imminent: 'You read about it [in the media] all the time, third time lucky for IVF couple or someone who gets pregnant after adopting a baby' (023).

Insufficient information specific to the individual

During interviews, comments regarding information provision were generally less positive than the responses in the questionnaires. In particular, information received appeared to be 'generic' and not specific to them as an individual couple. Respondents reported a sense of being 'unprepared' for the major step of 'decision-making' and felt that an additional appointment/s to discuss the effects of ending treatment would have been beneficial: 'I think another appointment would have been more helpful. I mean, we got such a shock when we were suddenly faced with negative comments. We need time to absorb that and come back and discuss things further' (079). Most wished that they had set themselves 'a limit' in terms of the number of cycles at the outset. Perhaps some patients require guidance towards making the decision to end treatment with information which is specific to them: 'I do think that couples need to be told to stop, and to find out why they have this driving force that keeps them going' (100). Planning for the end in the beginning was another sub-theme that shaped the component of individualized information. One couple was adequately prepared for the final decision to end treatment, in that they attended the consultation with a list of questions: 'We were prepared for our final appointment with every question you could possibly think of, but what worries me, is that if we hadn't asked all those questions, what would we be left with today? I got more information about my medical condition than I ever had before, and I wondered why this hadn't come earlier' (008). Patients felt that whilst on treatment, they were frequently given false hope of success and that any negative information which was available to the clinic staff should have been discussed with them prior to the final consultation: 'I think you should be honest with everyone in the beginning and all the way through'. Another respondent felt 'let down' in that essential information had been withheld in an attempt to protect her from the inevitability of miscarriage, which impacted on the decision-making process: 'I don't think it does us any favours to protect us from information that may initially be harmful' (008). This was reiterated by another respondent: 'Any piece of information;

however hurtful we may find it, is more helpful in the long-term' (147).

Social and professional opportunity costs

Most women had spent the majority of their thirties going through investigations and treatment resulting in a sense of 'missed opportunities', which eventually influenced their decision to end treatment: 'I was so drained throughout treatment and never felt sociable. We had a great social life before IVF and a part of me wanted that back so badly' (086). Many were unable or unwilling to share their concerns and anxieties with close family and friends, distancing themselves from potential support networks. One woman captured her own experience: 'One of my closest friends said that I had changed since starting IVF when I called off lunch yet again. ... I didn't feel sociable, but deep down I missed the social interaction. I suppose I was afraid that someone would appear with a baby or to say that they were pregnant, and I just couldn't cope with that. I had to stop [treatment]' (024). Infertility treatments were described as demanding and exhausting, leading to the avoidance of certain social activities: 'We cancelled social events; gave excuses and rearranged holiday plans' (016). IVF treatment also controlled many couples' social activities: 'Social commitments were worked around the IVF, not the other way round and you could never commit to anything or anyone when on treatment. So ending treatment allowed us to have a social life again' (008). Some women actually described feelings of relief at the end of treatment, with one woman explaining in detail how she could now move on with her life: 'I wanted my life back, and I remember feeling great sadness at the thought of never being pregnant, more than that, never having a child, but also a huge relief that I wouldn't have to go through another IVF cycle and the disappointment and grief that it brings' (029). Being released from the incredible stressful cycle of events that surround IVF treatment was expressed by another respondent: 'I'm still grieving for the child I never had, for my fertility, but I feel a sense of relief that I don't have to go through the emotional upheaval of another cycle and that we can now move on' (001). For many, infertility and assisted conception-related issues created a sense of 'life on hold'. One professional woman commented not only on her sense of failure as a woman, but in failing to meet the expectations at work: 'I missed two chances of promotion at work. I was beginning to think if I gave any more time to IVF, I wouldn't have a career' (086). As previously mentioned, women appeared to go through a period of critical self-reflection at the time of making the final decision: 'I've got a part of my life back. Freedom for the first time in years, and ... enjoying my life again' (018).

Physical and emotional pressure exerted on the couples' relationship

Financial pressure and the need to balance the conflicting demands of IVF, with those of an everyday social and professional life, caused frequent conflict within the marital relationship. Almost two-thirds of couples in Aberdeen

self-fund their IVF treatment, therefore, finance appeared to influence the final decision: 'We had spent over £12 000 [US\$22 080] on IVF; not that we grudged the money; I mean you can't put a price on a child, but it added to the stress of it all' (029). In addition, whether to have another cycle of treatment or not created further conflict: 'We just couldn't agree on whether we should have another cycle of IVF. Neither of us would admit we had really had enough, as you don't want to be the one who admits defeat' (086). The sub-themes that characterized the relief of the distress caused within the relationship included 'gaining control' and 'letting go of the learned helplessness' adopted, whilst on treatment. Many commented on physical and emotional pressure that IVF exerted on their marriage/relationship, often resulting in periods of depression: 'He [her husband] would have carried on, but I couldn't have coped with another disappointment, the anger and especially the depression—I just couldn't do it anymore' (139). As time went by, repeated failure led to despair and isolation: 'The constant stress and disappointment was incredible. Looking back, I would have risked my marriage for it all [a child/children]' (023). More often than not, one partner considered an alternative (such as adoption), to IVF, and one woman reflected: 'We have reached a decision based on what we are comfortable with ... and not on what other people think or have advised' (016).

Information provision and communication skills

The decision to end IVF treatment was formally taken at the final consultation with a clinic doctor. Many women felt that at this juncture, the information provided and communication between the clinician and the patients themselves could be improved. Contrary to the results of the questionnaire study (Peddie *et al.*, 2004), comments about information provision were generally less positive. Some commented on the failure of medical staff to put them at ease, and frequently expressed feeling 'uncomfortable' during the consultation: 'Doctors are very matter of fact, whereas the embryologists have more contact with us. We were able to ask them questions that we didn't feel comfortable asking the doctor. It was the embryologist that told us there was a specific egg problem after the second failed attempt, and that was helpful' (042), and many appeared to have consulted with a doctor who was unfamiliar to them: 'We never seemed to see a doctor that was known to us, that knew our history and knew what we had been through' (016). Many commented on the fact that some medical staff appeared to be unfamiliar with their treatment history: 'I was disappointed with the lack of time to fully discuss things, and the failure of doctors to attend consultations prepared. We often had to suffer the apparent unprofessionalism of doctors scrambling through notes for the first few minutes to establish the history and often being asked what the history was ourselves' (016). Women particularly appreciated professionals who were clear and direct in their information giving; in particular, those who were compassionate and familiar to them. Very few women appeared to have been given the opportunity to discuss the advantages and disadvantages of ending treatment, which may have influenced their experience of the decision-making process:

'I asked him about egg donation, but he [the doctor] said there was a two year waiting list, which told me he didn't really think it [egg donation] was for me' (039). One woman commented on the 'lack of counselling skills' of the doctor (at the unexpected suggestion of ending treatment) and his embarrassment when she started to cry: 'You, [nurses and midwives] were far more people orientated than the doctor, I mean he [the doctor] was clearly embarrassed when I got upset' (043). Another woman reflected on a similar situation where the suggestion of ending treatment came as a surprise: 'I felt so bad when I started to cry. I knew he [the doctor] couldn't cope with it as he shuffled my notes about and looked at the floor, anywhere but at me' (028). The nature of the consultation left many feeling inadequate and emotionally unsupported: 'The end could have been handled a bit more sensitively by the doctor, but that's possibly because for us, the outcome wasn't good' (043). This often resulted in women not asking specific questions, or not knowing what they should ask: 'The amount of questions in the questionnaire [quantitative study] made me question whether any of that had been discussed during my last consultation' (139). In the questionnaire study, the majority of women commented that they were not hurried into making the decision to end treatment. However, on clarification during interview, many commented on the apparent 'rush' of the doctor to end the consultation: 'Even if he had said, go away and think about it and come back when you feel ready to discuss it'. (016). Whilst some did not perceive the need for therapeutic counselling, others acknowledged the end of treatment as a time when counselling may be beneficial: 'To me communication is everything, and as for making the final decision to end treatment, enlisting the help of a counsellor at this stage would be a more sensitive way of going about it' (086).

Lack of continued support from the IVF unit

The need for continued support from the Unit some time after ending treatment appeared to be universal, as many recalled feelings of low self-esteem after making the final decision to end IVF treatment. The length of time they felt that contact should be maintained with the unit after ending treatment ranged from 3 to 15 months. With regards to satisfaction with the decision made, many commented that, in the period between the final consultation and the timing of this study, they frequently questioned whether the right decision had been made. However, some women demonstrated a gradual acceptance of life without children. Many women expressed feelings of isolation after the final consultation: 'We didn't know if we should expect any further contact from the unit. It wasn't explained to us, but a phone call would have been welcome' (079). Although many had support from their partners and/or friends, they felt that the staff offered them a support system that was different and that had been such an intense part of their lives for many years. Whilst women expressed feelings of satisfaction with communication whilst attending the clinic, they felt the system had failed them at the end: 'I really felt let down at the end. It's such a traumatic experience for everyone that I think you really need the support and help at that point more than any

other' (116). One woman recalled the doctor saying, 'the door is always open', which left her with a sense of 'security' and the knowledge that she could phone the Unit in the future (although she commented that she knew she never would).

Whose decision

The majority of women reconsidered their decision on several occasions, felt strongly that the decision to end treatment was theirs to make, and that this actually helped in the acceptance process. Many commented that it was they who had to live with the consequences, not the doctor. Although they respected the experience, knowledge and care from everyone involved, the final decision had to be theirs. The manner in which the doctor communicated with them appeared to affect the women's confidence, not only in the doctor, but also in the final decision made. The following quote characterizes many of the sub-themes (grief and relief), which shaped the component of 'the final decision made': 'I felt sadness, extreme sadness, but relief also. I'm happy with the decision and have absolutely no regrets about having tried IVF, after all, we did everything we possibly could to have child' (129).

Influence of the study

Women were unsure about participating in this study and often deferred making a decision for weeks: 'I didn't complete it [invitation to participate] straight away. I just ignored it. Maybe there was a hidden fear, I don't know but I surprised myself by coping with it. I didn't know how I would feel' (117). Some women commented that the study itself raised the issues of confronting an undeniable situation—childlessness: 'I hadn't thought about stopping treatment until today. I suppose it's made me confront issues that I should have addressed a long time ago' (011).

There were several discrepancies between questionnaire responses and those elicited during interviews. Women who had generally given positive responses to the questionnaires, frequently made negative comments during interview, which on clarification, reflected their perception of the experience 'as a whole'. For example, one woman stated that she was satisfied with the time the doctor took with her in the consultation, however during interview stated that 'we came out of there [the consultation] with more questions than we came in with, and there wasn't time to discuss them' (016). On asking her why she had ticked 'satisfied' with this aspect of care in the questionnaire, her response was, 'well he had spent about 20 minutes with us'. Given the constraints of clinic time, this woman felt she had been given adequate time for her consultation. Others clarified that they had ticked 'satisfied' rather than 'very satisfied' for several questions as they felt that certain aspects of information provision could be improved. We particularly wanted to examine the perceptions of women who had ticked 'neutral' [midpoint] responses to questions. Some gave the reason as 'not understanding the question'. One woman commented that she had read information on the internet; in particular, a research paper on blastocyst transfer. When she asked the doctor about this form of treatment, he said that it was not routinely offered in Aberdeen. Therefore in relation to

the question: 'The doctor gave me all the information I needed to understand the decision', she gave a 'neutral' response. Another woman commented that, 'I wasn't given information about other options or the advantages and disadvantages of stopping treatment, but because I never asked him [the doctor] about adoption or egg donation, I ticked neutral' (001).

Discussion

The results of this study indicate that the decision to end treatment forced women to come to terms with their unresolved infertility. Though difficult to make, it offered some women a way out of the emotional distress caused by IVF. Women identified limitations in terms of the quality of communication and the provision of post treatment support in the context of making their final decision.

This study was designed to explore some of the issues involved in decision-making at the end of IVF treatment in a way that quantitative studies are unable to do (Peddie *et al.*, 2004; Skea *et al.*, 2004). The analysis was undertaken by two researchers with contrasting backgrounds (clinical and sociological) who cross-checked the coding of the different themes within the transcripts (Carey *et al.*, 1996). The use of qualitative data collection allowed us to gain additional knowledge about the discrepancies between questionnaire and interview responses (Williams, 1994; Avis *et al.*, 1997; Williams *et al.*, 1998). This study was undertaken in a clinic where the respondents were known by the principal researcher (V.P.), and it was necessary to make the respondents aware of the distinction between research and 'therapeutic' consultation. During pilot interviews, it was difficult to avoid an element of counselling; however, the midwife recognized the importance of 'staying in role', and this was made explicit to the women being interviewed. As such, appreciation bias (Baker, 1994) may have been an issue, as women may have viewed 'research as therapy' (Bourguignon *et al.*, 1998). Twenty-three of the 25 interviews were conducted in the clinical area, which may be seen as disadvantageous in that the venue may have been associated with care provision. We asked the women to give 'retrospective accounts' of their perception of the decision-making process, and although many women demonstrated traumatic recall of certain events, we cannot ascertain whether their recent experiences influenced their responses (Daniluk, 2001; Hammarberg *et al.*, 2001). In common with most types of qualitative research, our sample size was relatively small; however, this is unlikely to compromise the quality of the findings as the sample included as wide a range of demographic characteristics and different causes of infertility as possible. As the emphasis was on women's perceptions of decision-making at the end of IVF treatment, data relating to the views of the male partner or the clinician undertaking the final consultation have not been captured. Despite its shortcomings, the authors believe that this study provides additional data in this area of infertility, and challenges critics of shared decision-making who suggest that most patients do not want to participate in treatment decisions with their physicians (Coulter, 1997).

Although satisfied with the overall communication and care received throughout treatment (Hammarberg *et al.*, 2001), certain negative experiences were identified which affected women's perceptions of the decision-making process. The qualitative approach exposed some discrepancies between positive responses in a previous quantitative questionnaire-based study on the same sample of women (Peddie *et al.*, 2004) and specific negative comments elicited at interview. In terms of coming to a final decision, many women had not yet reached the point of acceptance of involuntary childlessness. In common with previous work, the authors found that those who subsequently adopted children were more positive about their decision and no longer viewed themselves as 'childless' (Van Balen and Trimbos-Kemper, 1993; Bryson *et al.*, 2000; Daniluk, 2001).

Many women were initially reluctant to take part in the study, for fear of confronting issues they had yet to deal with. This element of denial appeared to be further borne out by comments about the possibility of future breakthroughs and spontaneous conception, and has been reported previously (Daniluk, 2001). Women felt that they were given false hope of success while they were attending for treatment, which affected or delayed the inevitability of acceptance of 'biological childlessness' and in turn, delayed the decision-making process. Financial constraints and age also influenced the final decision to end treatment (Lockwood, 1998), in that the outcome was likely to be influenced by a lack of resources rather than by deficiencies in the techniques available. These elements exacerbated the stress already experienced, as women described making the decision to end treatment as being 'very final'. However for some, it offered a way out of the emotional distress associated with IVF treatment (Rosenberg and Epstein, 1993; Leiblum *et al.*, 1998; Daniluk, 2001).

Women identified certain shortcomings associated with the final consultation at which the decision to end IVF treatment was made (especially where negative comments were introduced for the first time), and as a result, identified the need for further support from the IVF Unit. This may be viewed as being situation specific, in that receiving bad news was perceived as a negative experience. Some women found this traumatic and may have required more than one clinic visit to absorb the finality of the decision (Buswell, 1999). The manner in which the final consultation is approached appeared to influence women's perceptions of the experience of the decision-making process. Frequently, women said they 'did not know what they should ask', which appears to reinforce the inadequacy of the quality of information received at the consultation, which identifies with previous work on decision-making (Skea *et al.*, 2004). Improvements to the existing system of decision-making may be possible by adopting a framework (Bruce, 1989) in which clinical care in IVF is underpinned by sophisticated and effective strategies of information provision at the start of treatment, including written psychological information as described by Boivin *et al.* (1999). Whilst the authors do not advocate a check-list approach to consultations, they are in agreement with previous studies, in that the preparation of the patient for ending

treatment should be reinforced at each follow-up consultation between treatment cycles, with factual, individualized information (Slade *et al.*, 1997; Daniluk 2001; Hammarberg *et al.*, 2001), which facilitates autonomous choice (Gillon, 1991). It has been reported that where women perceived to be involved and 'in control' over various aspects of infertility treatment, the less likely they were to experience depression (Miller-Campbell *et al.*, 1991; de Lacey, 2002). Previous studies have also reported that people with high satisfaction with decision scores are more likely to 'follow through' with decisions made (Dulaney *et al.*, 1990; Skea *et al.*, 2004).

Psychological and emotional responses of couples at the end of IVF treatment have been studied previously. Bryson *et al.* (2000) and Daniluk (2001) examined how couples make the transition to biological childlessness, and how they reconstruct their lives after medical treatment fails. The present study examined the circumstances of the decision-making process at the end of IVF treatment, and the involvement of the woman, her partner and the clinician, prior to the transitional period. Some of the themes emerging from this study were similar to those previously identified. For example, while participants 'came face-to-face with the undeniable reality that their infertility was permanent' many experienced relief 'after finally being released from the endless emotional roller-coaster of medical treatments and repeated procreative failures' (Daniluk, 2001). Our results are consonant with those of Bryson *et al.* (2000) who found that although 'infertility continues to be a chronic source of stress, extending well beyond the treatment period', women who had subsequently adopted children possessed a greater degree of 'life satisfaction'. In common with our study, Bryson *et al.* (2000) also identified 'the need for better counselling, not only in preparation for treatment, but in the long term after treatment has failed'. This was also the conclusion of a study by Van Balen and Trimbos-Kemper (1993) who identified the need for emotional support and counselling in couples who remain childless.

In a different approach to the transition of 'life after IVF', Blenner (1990) described the predictable progression of couples with infertility through eight stages from 'awareness' and 'facing a new reality', to 'shifting focus' (from resignation in couples who remain childless to focusing on the child for those who subsequently adopt). A similar detailed exploration was outside the remit of the present study but excerpts from interviews suggest that women go through a process of adjustment before and after making their final decision to end treatment.

Slade *et al.* (1997) and Hammarberg *et al.* (2001) examined the emotional experience of IVF treatment. In a conclusion similar to ours, Slade *et al.* (1997) suggested that 'it is important that services should assume some responsibility for mitigating this impact by the provision of post-intervention psychological assistance'. Women's reasons for discontinuing treatment in our study were similar to those identified by Hammarberg *et al.* (2001) and included 'the emotional cost', 'inability to cope with more treatment' and the 'physical cost' of IVF.

Callan *et al.* (1988) aimed to predict and understand women's intentions about continuing or discontinuing IVF, including the role of social pressures. Areas for future study in the context of studying limitations of IVF decisions were identified as 'the role of husbands and doctors in the IVF-related decisions of women', 'the quality of the husband-wife and the doctor-patient relationship, and 'the patients' use of counselling support'. This study explores the doctor-patient interaction but adds limited data on interaction between the male and female partners or use of formal counselling as a support mechanism. While Callan *et al.* (1988) identified attitudes and social pressures as being important in shaping women's decisions about further IVF cycles, our study reveals that many women were not influenced by these issues.

Future research/recommendations

The perceptions of the male partner have not been captured in this study, therefore future research is required in this area. The possibility of increasing the time allocated for final consultations may increase women's perceptions and experience of the final consultation, and encourage a more positive decision-making environment. An investigation into the provision of a dedicated decision-making counselling session (Skea *et al.*, 2004), with either the unit counsellor or member of the nursing/midwifery team (after the final consultation) may be beneficial to these women. Previous studies have suggested that this may improve long-term satisfaction with the decision (Kaplan and Ganiats, 2004). The provision of an information pack prior to attending the consultation may be of benefit to these women in preparation for asking appropriate questions relevant to the decision being made with regards ending IVF treatment.

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