

Real Life Methods

Part of the ESRC National Centre for Research Methods at the Universities of Manchester and Leeds

Working Paper

Assessing Satisfaction: Insights from a multi-methods study

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April 2008

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1. Introduction

The data to be discussed in this paper arose from a study of the experiences of parents who had an unborn baby with a serious abnormality. The study used multiple methods to assess parents' satisfaction with aspects of their care which thus allow us some insights into methodological issues in the numerical rating of satisfaction. It is increasingly being recognised that 'satisfaction' is a complex construct whose measurement is problematic. There is a growing literature on this topic, including a systematic review published by the NHS R&D Health Technology Assessment programme (Crow et al 2002). In the present paper, we will outline some of the specific issues in measuring and defining satisfaction which arose in this study and which we believe have much wider applicability. Although they inevitably serve to draw attention to the limitations of numerical scoring of satisfaction, they also illuminate the concept of satisfaction and enrich our understanding of it.

A list of publications from the study, and from a parallel study which looked at health care professionals, is given at the end of this paper.

2. Methods

2.1. Participants and recruitment

This was the most comprehensive study ever undertaken of the experiences of parents who had an unborn baby with a serious abnormality. It took place in England in the late 1990s, funded by the NHS R&D Maternal & Child Health Initiative. The study was longitudinal and involved 247 mothers and 190 fathers: 148 women terminated their pregnancy and 72 continued. In the remaining 27 pregnancies, the diagnosis of abnormality was not made until the baby was born, although it could, in principle, have been made antenatally. These parents were included for comparison with those who continued their pregnancies in order to address the question of whether it is helpful for parents to have foreknowledge.

The study was limited to English-speaking participants because we considered it important that these sensitive issues were explored initially with parents who would not have had additional communication difficulties. Parents were eligible if they had received a diagnosis of a fetal abnormality where "there was a strong likelihood of a serious mental or physical handicap" i.e. a condition which would normally have led to the option of termination being raised by a health professional under Clause E of the Abortion Act.

Potential participants were identified and recruited 6-7 weeks after a diagnosis by four participating fetal medicine units, seven local district general hospitals and two voluntary sector groups. Respondents were telephoned on receipt of the consent form to collect basic information about the circumstances of the diagnosis and to explain more about the study. Participation involved four contacts: a questionnaire sent immediately; an in-depth, tape-recorded interview within the following few weeks (Time 1); a second questionnaire sent approximately one month after the baby's expected date of birth (Time 2); and a third questionnaire sent 13 months after the diagnosis (Time 3).

2.2. The interview

Interviews were carried out by one of seven experienced and sensitive interviewers, all of whom were female. The interviewer made it clear that she was independent of the hospitals and would not be feeding back personally identifiable information to any professionals involved. All interviews were tape-recorded and parents were told that they would be transcribed. Interviewers tried to maintain a strict chronology during the interviews with a focus on input from health professionals and how this came about, while remaining sensitive to the needs of the parents. At natural breaks in the narrative, parents were given a card with a printed 0-5 scale and were asked to score their satisfaction with the aspect of their care that they had just described e.g. satisfaction with care while undergoing prenatal diagnosis and decision making; satisfaction with care in hospital; satisfaction with aftercare. The scale was anchored at 'not at all' and 'completely'. In some interviews where scoring appeared incongruous with the account given, the interviewer probed the reasoning behind the rating. Interviews lasted an average of 2 hours; only two were less than one hour while 10 were more than 3 hours.

All interviews but one took place in the parents' home. No father agreed to take part without the mother and no parents asked to be interviewed separately, although this option was offered. In the interview extracts M stands for Mother, F for Father, and I for Interviewer. All parents' names have been replaced with [Mother] or [Father] as appropriate. The 4 digit number following a quotation is the couple's unique study identification number.

2.3. 13 month follow-up

Postal questionnaires sent at 13 months post-diagnosis (Time 3) assessed a number of psychosocial outcomes using both open and closed questions and validated psychological measures. Parents were again asked to rate their satisfaction with the different aspects of their care.

2.4. 'Control' group – the Retrospective Study

Because we recognised that participation in a longitudinal research study is itself an intervention, the design also incorporated a second group of parents with whom we had no contact until 13-month post-diagnosis (the Retrospective Study). These parents received only a suitably modified version the Time 3 questionnaire. The comparison between parents in this group and parents in the longitudinal study was designed to tell us to what extent our findings might be generalisable to parents who had not been part of a longitudinal study. The data presented here are taken only from parents in the longitudinal study unless otherwise indicated.

3. What people are scoring

In a number of cases there appear to be discrepancies between numerical ratings and the experiences reported. One woman described an apparently informative ultrasonographer who organised rapid referral to the main hospital and support from a midwife in the interim. The woman then gave a satisfaction score of 0 saying:

At the clinic. It was the way it was said. I was glad they told me, but it was just the way that they told me. They just blurted it out. There was no preparation' (2231)

This case highlights the difficulties that parents face in summing up a multi-faceted experience in a single number. By examining all of these occurrences we were able to identify themes to these mismatches which we present in this section.

3.1. The practical vs. the emotional

While some parents made it explicit that they had chosen an average which took account of a range of individuals or of different feelings about technical or practical aspects of care compared with the more emotional ones, others respond to only one aspect. Thus the mother above related her dissatisfaction to how she was given the information about the diagnosis and its emotional impact and did not ascribe importance to the information and the practical follow-on. Other parents, however, prioritised the practical and technical aspects of the care they received over and above any emotional impact and even managed to ignore behaviours with which they expressed considerable dissatisfaction. For example one mother said '*I'd probably say "completely" [i.e. satisfaction score = 5], because I haven't got a bad word to say about [local hospital]*'. However, she also described how, in one part of the diagnostic process, she had felt ignored by two ultrasonographers as they talked about her but not to her:

...That's like treating you like a little piece of fat on the floor. I thought, I'm not, you know, I'm here, and I've got feelings. I do not need this. You know, I'd like a little bit of an explanation. If she would have said, right then, I can see some problems. I'm going to go, and I'm going to get two consultants, who are experts, and they are going to come and look at it. An explanation would not have gone astray.(2060)

3.2. The system versus the individuals concerned

Some parents who were happy enough with the care that they personally received, nonetheless rated it as less than completely satisfactory because they are critical of the system.

Their comments generally focused on being lucky with the individuals that they came into contact with:

it was just the GP's own sensitivity (2005)

I don't think another midwife would if she hadn't been my friend (2007)

In a similar way, some parents focused not on individual health professionals but on themselves as individuals and commented *that 'it wouldn't have done for someone else who wasn't coping as well as I was'*. In both cases, a low satisfaction rating is commenting more on the system and what is available for parents in general rather than necessarily on any failure to meet their own specific needs.

3.3. Whether to rate absence of care

Some parents have rated their satisfaction only with the services received e.g. midwife visits; services which may have been wanted but not received, e.g. a counsellor, are not taken into account in the rating. This reflects an inadvertent ambiguity in the question '*how satisfied are you with the care you received?*' Conversely, some parents who have received no care are able to rate that as perfectly satisfactory if they did not actually want any. Others rated it as unsatisfactory by its absence, irrespective of whether they would have wanted it. This was a particular dilemma for the fathers especially in discussing feelings about care after a termination: '*To me it's irrelevant because I've not received anything.* (2016)

3.4. Care that is offered vs. care sought

This distinction was important to many parents:

M: I think it should have been automatic. I don't think I should have had to have asked for it. I think it should have been part and parcel of the same thing. I think aftercare was very poor. (1055)

and:

F: I say I make that a zero because there wasn't any follow-up.

M: Yes, but I did go to the doctors.

F: Yes, but you went to the doctors ...

M: Well, yes, but that's why I've only given it a 2. (2015)

So some parents, although satisfied with the content of their care, gave it a lower rating because they had had to initiate it. Relating to this, some parents even disregarded a particular source of support/care in their assessments because it was not offered to them spontaneously or routinely.

3.5. Care offered vs. care received

For some parents, the offer of care (or, as above, failure to offer it) was the key aspect, whereas for others it was actual receipt of care. This seems to relate to perceived needs and will be discussed further below.

3.6. Rating against an 'ideal' or a 'realistic' yardstick

There are a few cases where the care received appeared to be very good, but where parents were not completely satisfied because they had other unmet needs which could not realistically be met by the healthcare system e.g. a listening ear familiar with their circumstances available 24 hours a day as wished for by one mother (1053). So here the question is being answered against a yardstick of an ideal, whereas most parents answered the question focusing more on what health professionals did compared to what they might reasonably have done (e.g. the midwife came round every day), rather than on whether they had had unmet needs.

3.7. Ambiguity about the scope of the care being rated

Trying to sum up an entire aspect of care inevitably left open ambiguities. Our use of phrases such as "the care you received prior to making your decision" and "the care you received since you left hospital" had been deliberately unspecific

to allow for different circumstances, but this unfortunately created scope for different interpretations. The particular ambiguities that were evident from parents' responses concerned the inclusion/exclusion of community based health professionals as opposed to those from the hospital, and inclusion/exclusion of support from non-health professional sources e.g. support groups.

3.7.1 How the question is asked

When questions about satisfaction are only in a questionnaire, then all individuals responding to that questionnaire are, we hope, answering the same question. Even with that consistency, people interpret questions differently. Within this study, although the question was written on paper and given to parents to complete, the question was asked by the interviewer. As such the way in which the question was asked varied, both between and within interviewers. This will have added to the ambiguity mentioned above for some parents. Furthermore, the amount of qualitative data concerning why a particular score was given varied with the amount of probing that the different interviewers might have undertaken. This also would vary between interviewers depending on the nature of the interview and the state of the parents at a particular time within the interview, since sensitivity to the parents emotional state was paramount during interviews.

4. Expectations

It is evident that for many parents 'satisfaction' is a statement about the match, or mismatch, between what they received and what they expected. Because very few of the parents had been in the same situation before, their expectations came from a number of sources. The most common scenario to draw on was that of normal childbirth. In this study, parents who terminated their pregnancy generally reported a high standard of care in hospital while undergoing the termination. The high levels of satisfaction reported in some cases reflected a *higher* standard of care than the parents had experienced for live born children. Furthermore, some parents specifically said that they had expected poor care, at least in terms of the attitudes of health professionals, because they expected to be criticised for having made the decision to terminate a pregnancy.

Within this study, it was only in this context that prior expectations that had been met and even surpassed were described. More usually, prior expectations were only described when they were not met. This was particularly true with parents' comments about post-termination care. Parents had expectations, based on experiences or knowledge of what happened to women who had had babies and there was a mismatch between these expectations and the reality:

F: I mean when you've actually successfully had a baby, they come round, don't they? (1052)

M: My experience is that I had a baby, so just because he didn't live doesn't mean to say that I'm not like everybody else who has had a baby that lives. (2030)

Other parents also drew on previous experiences of miscarriage, for example, one mother (2015) was amazed not to be offered counselling after her

termination when this had been offered, at the same hospital, following a previous miscarriage.

Expectations were also sometimes based on knowledge of the health professional concerned. Parents would express surprise if a health professional with whom they had had a relationship did not initiate contact.

Some parents were explicit that they found it difficult to rate satisfaction because they had not known what it was appropriate to expect from health professionals:

M:... you're satisfied as far as you know, but you would be very unsatisfied having found out in a month's time that you should have done this and you hadn't done it. (2003)

There were a number of cases where specific expectations had been raised by health professionals themselves which were then not realised. For example, a number of parents were told when they left hospital that community health professionals would be informed, which led to the expectation that contact would be forthcoming, and this seemed to lead to greater disappointment when no contact was made. One couple (2083) had been fortunate to build up an excellent relationship with a hospital-based health professional who had supported them throughout the process of testing, diagnosis and termination and who had said that she would come and visit them at home afterwards. Although she did ring twice, and attended the funeral, she did not actually visit and the parents clearly felt very let down by this.

5. Retrospective rating of satisfaction

We cited above the mother who said that '*you're satisfied as far as you know*'. This highlights another aspect of satisfaction which needs consideration across all of the themes in this study: when parents talk about satisfaction, they are not only describing their recall of events as they perceived them *at that time* but also considering aspects which they have discovered subsequently.

For example, one mother had expressed dissatisfaction that her hospital appointment was delayed such that her termination could not happen until 15 weeks; she subsequently discovered that the delay had further implications for herself as well as for those performing the termination, which added to her dissatisfaction:

But it wasn't until afterwards, I hadn't actually realised, because I was so far gone, I hadn't actually realised how they perform a termination, which is actually to take the fetus out in pieces....Um... but it hadn't sort of occurred to me, you know. I had wondered, you know. But it hadn't occurred to me, and I was quite shocked at this TV programme. (2043)

Discovering additional information after an event is also a source of dissatisfaction that can only be expressed at a later point:

I was very cross with them when I found out that I could have had the SATFA [support group, now called ARC] handbook, and they

didn't give it to me. And after I read it, it was after the termination, I said, wow, this is exactly what I needed before the termination.
(2118)

5.1. Looking back a year later

Much of the data presented in this paper draws upon the in-depth interviews carried out with parents in the longitudinal study 8-10 weeks after the event. However, parents were also asked to look back on their care and re-rate their satisfaction. They were also invited to make any further comments about their care in those follow-up questionnaires.

Because comparison with parents in the retrospective study can only be made on these data, it is important that we try to understand the relationship between what parents were saying face-to-face straight after the event and what they said in a postal questionnaire a year later. Unfortunately, the wider literature on the measurement of satisfaction appears to have little to say upon this important issue.

5.2. Correlations over time and within couples

Focusing just on those parents in the longitudinal study who terminated pregnancies, we are able to look at the relationships between ratings of satisfaction with the three main aspects of care examined: care up until getting the diagnosis at the booking hospital; care in hospital while terminating the pregnancy; and aftercare. One hundred and seventeen sets of parents (i.e. both mother and father) returned the final questionnaire.

As Table 1 shows, parents' ratings over time were moderately consistent with values of Spearman's rho of over 0.6 for mothers and between 0.46 and 0.56 for fathers¹.

Table 1 Correlations between satisfaction ratings at Time 1 and Time 3

	Spearman's rho ^a	N
Mothers		
With getting a diagnosis	0.624	104
In hospital	0.624	110
After leaving hospital	0.675	106
Fathers		
With getting a diagnosis	0.561	69
In hospital	0.462	69
After leaving hospital	0.581	68

^a p<0.001 in all cases²

Correlations were higher for mothers than for fathers. This is possibly because at interview, when both parents were rating together, fathers were more likely to go along with mothers' ratings, whereas at Time 3 they were more likely to be alone and thinking of their own experiences and feelings about them. Such a

¹ Rho = 1 if the scores are perfectly correlated and 0 if there is no relationship

² the p value indicates how likely it is that a i.e. a finding would occur by chance.

p<0.001 means less than one chance in a thousand

suggestion is supported by the finding that correlations within mother-father pairs were much higher at Time 1 than at Time 3. (Table 2)

Table 2 Correlations of satisfaction ratings between mother and father pairs

	Spearman's rho	N	p
Time 1			
With getting a diagnosis	0.796	97	0.000
In hospital	0.714	99	0.000
After leaving hospital	0.767	97	0.000
Time 3			
With getting a diagnosis	0.344	73	0.003
In hospital	0.423	72	0.000
After leaving hospital	0.407	72	0.000

5.3. Is satisfaction lower a year later?

5.3.1. Mothers' ratings of satisfaction with aftercare over time

Initial inspection of mothers' satisfaction with post termination care showed that this was rated as significantly less satisfactory in the final questionnaire than it had been at interview (Sign test³, $z = -2.52$, $p=0.01$, two tailed).

This is a potentially important finding with a number of possible interpretations. The first is that it is not an important finding at all, but a type I error, i.e. one of the inevitable chance results that will be obtained when a great many tests of significance are carried out. We therefore returned to the qualitative data and examined a subsample of cases.

Within the first 34 cases subjected to detailed qualitative analysis, 31 mothers had returned the final questionnaire and 17 had added comments to their rating of aftercare. The majority of these comments (12) were negative, or identifying shortcomings in care, one was neutral (she hadn't wanted any care) and only four were positive. The overall tone was therefore indeed more negative than the comments made at interview. Thus, the qualitative data in the final questionnaires do support the quantitative findings.

So, if mothers really are reporting lower satisfaction with their aftercare a year later, what might this mean? The differences could be

- a result of the passage of time
- a function of the method (postal questionnaire vs. face-to-face interview)
- a function of having already discussed these issues at an earlier stage.

The first possibility is that what we are seeing is a general trend, that is, that people express higher satisfaction just after an event than they do a year later. This is plausible, for example, as we have already noted, parents may make subsequent discoveries that cause them to re-evaluate their experiences. Unfortunately, there appears to be no methodological literature to support or

³ A sign test involves scoring each pair of time1-time3 scores as plus (Time 3 higher than Time 1), minus (Time 3 lower than Time 1) or the same, and then testing the resulting numbers of pluses and minuses against a chance distribution.

refute this possibility of a general trend, although it is something that we have also observed in another study (unpublished).

The second possibility - that people express less dissatisfaction face-to-face than they do in the relative privacy of a questionnaire - is also plausible given what is known about these different methods of collecting data. However, it could equally be argued that the in-depth nature of these interviews would have been *more* likely to uncover dissatisfaction than a structured questionnaire. Thus in interview, possibilities of care were raised with parents when they were asked about health professionals who might have offered them something that they might never have previously considered. We may of course, be seeing an interaction, in that the prior interview may leave parents feeling more able to express negative sentiments in a questionnaire than they would otherwise have done.

These lead us on to the other main possibility, which is that the process of taking part in the research, including detailed discussion of their care and its possible shortcomings, has led people to a more negative evaluation. This possibility would be entirely in line with recent findings on post-trauma debriefing (Small et al 2000).

These explanations lead to different predictions about the relationship between the responses of the longitudinal study participants and those in the retrospective study. If lower satisfaction is the result of the passage of time, or if it is a function of method, then both groups should be equally affected. However, if responses were influenced by the prior interview, then we would expect parents in the retrospective study to be expressing higher satisfaction, if the care women in each study group received was similar. In fact we did find that parents in the retrospective study had significantly higher satisfaction scores for all phases of care, but we also found that there were a number of differences between the samples including, critically, apparent differences in the care that they received. Our data therefore, although suggestive, are not quite as helpful in distinguishing between the competing explanations as we had hoped.

5.3.2. Other ratings over time

In view of the potential implications of these findings for mothers' satisfaction with aftercare, Time 1 and Time 3 scores were examined for each of the other phases of care for both mothers and fathers. The results of the sign tests are given in Table 3 and show that none of the others are significant, although the negative Z scores indicate a general tendency to lower scores at Time 3. Satisfaction with care in hospital was, however, so high at interview that it is only likely to go down.

Table 3 Comparing satisfaction scores between Time 1 and Time 3 (Sign Tests)

	z	N	p
<u>Mothers</u>			
With getting a diagnosis	0.000	104	1.000
In hospital	-1.622	110	0.105
After leaving hospital	-2.520	106	0.012
<u>Fathers</u>			
With getting a diagnosis	-0.884	69	0.377
In hospital	-0.158	69	0.874
After leaving hospital	-1.327	68	0.185

In summary, five out of six sign tests are not significant, and therefore do not support the hypothesis that satisfaction is rated lower a year later. It is only mothers' ratings of satisfaction with aftercare which show this effect and this may be a chance finding. Nevertheless, in the course of examining this evidence we have raised some potentially important methodological issues which would benefit from further study.

5. How does 'satisfaction' relate to 'mood'?

Many studies find a relationship between 'satisfaction' and 'mood' (Green et al 1998). However, this could mean at least four different things:

- being satisfied/dissatisfied results in people being happier/less happy
- being happier/less happy results in people assessing themselves as satisfied/dissatisfied
- dispositional characteristics (personality) lead people to respond more or less positively to ratings of both satisfaction and mood
- satisfaction ratings are no more than a crude measure of mood

It is surprisingly difficult to distinguish between these different interpretations of the relationship between mood and satisfaction in general. One approach is to look at the ratings that the same individual has given to different aspects of care at the same time. If these are not highly correlated, then this suggests that there is some specificity to satisfaction ratings that is not just a reflection of mood or disposition. In this study, the correlations between satisfaction ratings given at the time of the interview by mothers who terminated their pregnancies for the three main phases of care range from 0.21 to 0.32. These are all statistically significant. Of course, it is perfectly plausible that the relationships arise from consistencies in the standard of care received at different times, but it may also mean that there is a contribution of mood or disposition. On the other hand, these correlations are low enough for us to reject the suggestion that these ratings are *only* an expression of mood or disposition.

We can say nothing from this study about the relationship between individuals' personality and tendencies to be satisfied or not, but the study does lend some insights into ways of thinking about the possibilities raised.

Firstly, in the context of the devastating event experienced by the parents who have terminated pregnancies and the grief and sadness that accompany that event, it is difficult to envisage satisfactory care being sufficient to make women happy. However, we did find that dissatisfaction with one aspect of care, getting a diagnosis, was associated with low mood. A possible explanation of this lies in what is known about the impact of how a diagnosis is given. The term 'flash-bulb memories' has been applied to parents' memories of how they are told about a child's disability (Cunningham et al 1984). This phrase defines the clarity with which parents are known to remember such an event and the startling impact of that news. A poorly delivered diagnosis to parents who feel unsupported at this time may well act as a trigger to emotions akin to post-traumatic shock and result in additional grief over and above that attributable to the nature of their sad situation.

Secondly, this study did provide some evidence to dispute the possibility that satisfaction ratings are no more than a crude measure of mood. Although measures of satisfaction were correlated, only one measure, satisfaction with getting a diagnosis, as described above, was correlated with mood. If we were to have hypothesised about an aspect of care that would have related to mood it would have been satisfaction with aftercare: parents who get good and supportive aftercare would be both satisfied with the aftercare and their psychological health might be improved by supportive professional input. We found no such association, however.

Finally, if being happier results in people assessing themselves as more satisfied we would have expected to observe an increase in satisfaction over the course of the study because emotional well being improved over that time.

6. Summary & discussion

We have drawn attention to the limitations of numerical scoring of satisfaction, especially by a simple 0-5 measure, and have been both critical and supportive of our own methodology in assessing satisfaction with the care parents received at various times. We identified a number of areas that confirmed the difficulties of measuring satisfaction and interpreting responses, i.e. understanding just what and why individuals have scored in a particular way. But we also suggested that using a single item to measure such a complex issue, with the opportunity presented by an in-depth interview, does enable individuals to score satisfaction according to attributes that they consider important and not just those attributes of care that reflect the researcher's perspective (Calnan 1988).

In highlighting how some parents are concerned with practical aspects of care and others with their perceptions of how that care is delivered, our data support two of the psychological models that have been used to account for satisfaction: Korsch's model (Korsch et al 1968) of affect and Ley's (1977) model of cognition. Quine and Rutter (1994) have used both of these quantitatively in examining parents' satisfaction with how they were told of a child's disability and identify each factor as contributing to satisfaction. Different parents have identified the different dimensions of care that they relate to satisfaction, as identified in a study by the Health Policy Advisory Unit (1989): medical care, information, physical facilities, the environment, food, nursing care and visiting arrangements. Issues to do with expectations, whether parents have them, discuss them if met or discuss them only if not met, are clear within the accounts of parents within

our study and will allow for an exploration of the impact of expectations on perceptions of care in further analyses.

We have raised as an area for future research issues to do with changes in satisfaction over time. The qualitative data that has informed the satisfaction scoring at interview is not, of course, available when scores are obtained from questionnaires only. We have also raised questions concerning the relationship between mood and satisfaction and this is an important area for future research.

In their review, Avis et al (1995) discuss 'unresolved issues in the measurement of patient satisfaction' and raise a number of these issues. They are critical that 'patients' are seen as an easy source of data about how an aspect of the health service functions when they fill in satisfaction surveys, that satisfaction surveys assess health care processes and not outcomes and that researchers define the components of interest. Some of these criticisms can be levelled at our measurements of satisfaction but in combining a qualitative and quantitative approach we present our data as a contribution to methodological aspects of research in satisfaction, but also as a picture of how parents feel about aspects of their care. In particular we would reinforce the call of Avis et al (1995) for more qualitative forms of '*service evaluation that avoids treating service users as sources of data and, more importantly, can lead to improvements in care which are fully grounded in patients expressed values and aspirations*'.

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7.2 Publications from the parent study

7.2.1 Full report

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Copies of the full report are obtainable from Ombretta Orsini (Unit Administrator) at the Centre for Family Research, University of Cambridge oo203@cam.ac.uk)

7.2.2 Journal articles & book chapters

Statham H. (2002) Prenatal diagnosis of fetal abnormality: the decision to terminate the pregnancy and the psychological consequences *Fetal and Maternal Medicine Review* 13: 213 – 247.

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7.2.3 Published conference abstracts

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