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Maternal coping, appraisals and adjustment following diagnosis of fetal anomaly

Running head: *Maternal coping following diagnosis of fetal anomaly*

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What is already known about this topic?

- Many women are unprepared for a prenatal diagnosis.
- Following diagnosis of fetal anomaly, many women who continue with the pregnancy experience high levels of distress and between 58-93% of pregnancies are terminated.
- Although several factors have been associated with maternal coping and adjustment after a diagnosis of fetal anomaly, so far how women who continue with their pregnancy appraise such a prenatal diagnosis has not been investigated.

What does this study add?

- Satisfaction with and number of people providing social support, primary challenge appraisals, emotion-focused and problem-focused coping were associated with improved maternal adjustment following birth of their baby diagnosed with fetal anomaly.
- Following prenatal diagnosis and for the remainder of pregnancy, particular attention should be paid to older mothers, those experiencing additional stressful life events and those with less social support, as they may experience greater distress after childbirth.

Abstract

Objective: So far, associations between appraisals, maternal adjustment and coping following diagnosis of fetal anomaly have not been investigated in women who continue with their pregnancy.

Method: This study measured maternal coping and adjustment after and appraisal of a diagnosis of fetal anomaly in 40 mothers who had continued with their pregnancy using a cross-sectional questionnaire design.

Results: Based on retrospective reporting, 35% of participants met full diagnostic criteria for post-traumatic stress disorder after having received the diagnosis. Women were significantly more depressed ($p < .001$) and anxious ($p < .001$) and reported significantly less positive affect ($p < .05$) after having received the diagnosis in comparison to the time after childbirth. There were no significant differences between emotion- and problem-focused coping. Stressful life events, women's age, number of people providing support and problem-focused coping explained 57.6% of variance in anxiety and depression after childbirth. Satisfaction with social support, emotion-focused and problem-focused coping significantly explained 40.6% of variance in positive affect after childbirth.

Conclusion: Following a prenatal diagnosis and for the remainder of their pregnancy, particular attention should be paid to older mothers, those experiencing additional stressful life events and those who are socially isolated, as these women may experience greater distress after childbirth.

Keywords: coping, appraisals, fetal anomaly, stress, diagnosis

Maternal coping, appraisals and adjustment following diagnosis of fetal anomaly

Introduction

Early identification of fetal anomalies is intended to allow women and their partners reproductive choice¹⁻³, adjust to having a child with a disability, and consider managed delivery in a specialist centre or intrauterine therapy⁴. Many women are unprepared for such a prenatal diagnosis⁵, and experience shock, anxiety, and posttraumatic stress symptoms⁶⁻⁸. Between 58-93% of pregnancies are terminated⁹⁻¹¹, particularly in older women^{12,13}. Although there is now a body of evidence on the emotional impact of a diagnosis of fetal anomaly⁵, few studies have focused on how women who continue with the pregnancy after such a diagnosis cope^{7,14-18}.

The effectiveness of contact with specialist health professionals in discussing the prenatal diagnosis has been found to reduce maternal anxiety^{7,17,19,20}. Lack of certainty over the diagnosis has been associated with higher levels of anxiety, leading to difficulties in parental coping^{17,18}, possibly as this limits attempts to engage in problem-focused coping¹⁵. In the general population, satisfaction with social support and the use of more effective coping strategies has been associated with lower levels of distress²¹.

Following diagnosis many women who continue with the pregnancy experience high levels of distress and report that the remainder of their pregnancy is significantly altered^{7,15,22}. They engage in a range of strategies in order to cope, such as seeking support, using spiritual beliefs, staying busy, speaking to others with similar experiences, obtaining information from health professionals and the internet about the diagnosis^{7,17}.

The cognitive model of stress and coping²³ seems relevant to understanding how women cope after receiving a prenatal diagnosis. Here, cognitive appraisals and coping are proposed to mediate the outcome of stressful life events. Coping is defined as a person's "constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the person's resources" (p.141).²³

Coping serves two functions: to regulate emotions (emotion-focused coping) and to alter the stressful event (problem-focused coping). Generally, greater perceived control is associated with higher levels of problem-focused coping, whereas less perceived control is associated with higher levels of emotion-focused coping. Both primary and secondary appraisals converge to determine whether an event is perceived as stressful. They refer to an individual's evaluation of an event's personal significance and the adequacy of their resources for coping. Primary appraisals include consideration of potential loss, threat or challenge, and are influenced by a person's beliefs, values and commitments. Primary appraisals of threat and/or loss are associated with emotion-focused coping, whereas primary appraisals of challenge are associated with more problem-focused coping²⁴. Secondary appraisals consider an individual's ability to control or change an event's outcome with regard to their available coping (internal or external) resources. If the stressor is perceived to exceed the person's available coping resources then it is viewed as stressful, and determines the intensity of accompanying emotion.

Both positive and negative emotional attitude, which can be compared to emotion-focused coping, are associated with a reduction and increase in anxiety respectively, whereas active coping, similar to problem-focused coping, is not correlated with anxiety following prenatal diagnosis²⁵. Furthermore, emotion-focused coping facilitates better adjustment than problem-focused coping in women following termination of pregnancy²⁶. However, contrary to this finding, others¹⁸ found that engaging in problem-focused coping following prenatal diagnosis was related to positive psychological well-being and reduced levels of distress. Use of negative coping strategies, such as depressive coping, pessimism, cognitive avoidance, control of emotions, social isolation and regression, was associated with high anxiety and low mood at six months post-diagnosis²⁷. High levels of anxiety may also impede the individual's ability to engage in helpful coping strategies²⁵ and are predictive of negative psychological outcome at follow-up²⁷.

Although several factors have been associated with maternal coping and adjustment (level of psychological distress) following a diagnosis of fetal anomaly, so far how women appraise a prenatal diagnosis has not been investigated. The current study aimed to identify predictors of coping and later adjustment and to understand the role of appraisals in women who continue with their pregnancy following a diagnosis of fetal anomaly.

Method

Participants

Women over the age of 16 were eligible for inclusion in the study if they had received a diagnosis of fetal anomaly during prenatal testing; their babies were born between six months and up to three years previously and were alive at the time of completing the questionnaires; and spoke English fluently enough to complete questionnaires. Women with childbirth less than 6 months prior to participation were excluded because it was felt that the questionnaire might cause too much of a burden at a time in which the parents are still mastering transition to parenthood; and we excluded those greater than 3 years from childbirth as accurate recall of pregnancy-related events might be more difficult.

Women were identified by specialist midwives working within a pre-natal diagnosis unit of an NHS university hospital who sent them an invitation letter and reply slip. In addition, an advertisement for the study was placed on websites of relevant UK charities. Midwives invited all eligible participants without any screening procedure.

Women could either request a questionnaire pack (including covering letter and information sheet) by post or complete the questionnaires on-line or complete the questionnaires via telephone. Women were deemed to have given informed consent to participate in the study if they completed the on-line questionnaires, but were required to sign a consent form if they completed the questionnaires via post or telephone. Women were also

given written information about where to obtain support. This study was given approval by the local NHS ethics committee.

Measures

Women were asked to complete one questionnaire pack retrospectively, thinking back to the time between diagnosis and *before* giving birth (T1), whereas a second questionnaire pack assessed how women felt currently, *following* childbirth (T2). The HADS and ABS questionnaires were administered twice because they were the main outcome measures. There was concern that administration of all questionnaires at T2 could constitute too much of a burden and discourage participation.

*Hospital Anxiety and Depression Scale (HADS)*²⁸. This is a 14-item self-report questionnaire of anxiety and depression, which was completed for T1 and T2. Each item is rated on a four point scale, with a maximum possible score on each subscale of 21. A score between 0 and 7 is considered within the normal range, 8-10 signals mild anxiety and depression, 11-14 moderate and 15-21 severe. Caseness is assumed if the sum of all 14 items is ≥ 12 ²⁹. The HADS is both reliable and has satisfactory internal consistency³⁰.

*Affect Balance Scale (ABS)*³¹. Positive affect was measured for T1 and T2 using the five statements reflecting positive feelings of the ABS, which is a 10-item rating scale assessing psychological well-being. Questions were presented in a yes/no format and a positive affect score was obtained by summing the responses for the five items, with possible scores ranging from 0-5. The ABS has modest retest reliability and internal consistency³².

*Posttraumatic Diagnostic Scale (PDS)*³³. This was used to measure symptoms of posttraumatic stress disorder (PTSD) at T1. The PDS is a 49 item self-report measure, which assesses symptoms of PTSD using the Diagnostic and Statistical Manual-IV-TR criteria (DSM-IV-TR)³⁴. It indicates whether women meet full or partial (at least one symptom in each of the

three clusters) criteria for a diagnosis of PTSD³⁵. Part one uses a four-point Likert scale and yields a total PTSD symptom severity scale (0-51). Part two asks women to rate impact on functioning as a result of the diagnosis, using a yes/no format. Part three asks women to rate the extent to which the diagnosis interfered with work, social life and family life using a 10-point rating scale. The PDS has good internal consistency and test-retest reliability³⁶.

*Life Stress Scale of the Parenting Stress Index (PSI)*³⁷. This provides an index of the amount of stress outside the parent-child relationship that the parent has experienced and was used to collect information about stressful life events at T1. A score ≥ 17 indicates a high level of stress. The PSI has good internal consistency and test-retest reliability³⁷.

*Social Support Questionnaire 6 (SSQ6)*³⁸. The SSQ6 asks women at T1 to list how many people provided support (0-9) and to rate the satisfaction with this support on a six-point Likert scale, providing two subscales: mean of number of people providing support and mean satisfaction with support. The SSQ6 has good internal reliability for both the number and satisfaction subscales³⁸.

*Appraisal of Life Events Scale (ALE)*³⁹. Primary appraisals were assessed for T1 using the ALE, measuring three types of primary appraisals; threat, loss and challenge. Women were asked to rate their perceptions of the prenatal diagnosis using 16 adjectives presented on a five-point Likert scale. The ALE has excellent internal and test-retest reliability, and good construct validity³⁹.

*Coping Options*⁴⁰. Secondary appraisals were assessed using four items that describe coping options using a five-point Likert scale referring to T1. No information is available regarding reliability and validity of this measure; however, the questions correlated well with coping in one study⁴⁰.

*Coping Operations Preference Enquiry (COPE)*⁴¹. Coping was measured using the situational version of the COPE, which consists of 14 subscales. Items were phrased in the past

tense in order to be completed retrospectively (T1). Women were asked to indicate how much “each of the behaviours listed help [them] deal with the diagnosis” using a four-point Likert scale. The subscales of the COPE have satisfactory test-retest reliability⁴¹.

Demographic information. Women completed a brief demographic questionnaire about themselves and their child (Table 1).

Data Analysis

Data was analysed using the Statistical Package for Social Sciences version 16.0⁴². As almost all data was non-normally distributed, and transformations were not useful, non-parametric tests were performed throughout for continuity (either Mann-Whitney U or Wilcoxon Signed-Rank tests), with the exception of regression analyses. In terms of categorical data, Fisher’s exact test was used, as assumptions were not met for chi-square tests. Correlations were performed; however, Bonferroni’s correction was not used as it may have increased the number of type 2 errors⁴³. Two hierarchical stepwise regressions were performed on adjustment (measured by total HADS score and positive affect) at T2.

Results

Sample Characteristics

Forty women completed the questionnaires. A sample size of approximately 40 participants was needed as a large effect size ($R^2 = .26$) was anticipated⁴⁴. Thirty-six women completed questionnaires on-line, three via telephone with the researcher, and one via post. A further 19 women indicated on-line that they had read the information sheet but completed no further information. In addition 18 women completed the eligibility criteria and demographic information but did not answer any further questions. Of these women, 14 (77.8%) completed

information about their child. The overall response rate was 40/77 (51.9%). Information about completers and non-completers is presented in Table 1.

Insert Table 1 here

There were no significant differences between the completers and non-completers in any of the variables analyzed.

Distress and positive affect

Table 2 shows the prevalence of symptoms of depression, anxiety, positive affect, and PTSD diagnosis and symptom severity, as well as information about life events and social support at T1 and/or T2. Wilcoxon signed-rank tests indicated that women were significantly more anxious ($z = -4.01, p < .001, r = 0.45$) and depressed ($z = -4.13, p < .001, r = 0.46$) and had a higher total HADS score ($z = -4.32, p < .001, r = 0.48$) at T1 than T2. Women reported experiencing significantly more positive affect at T2 than T1 ($z = -2.9, p < .05, r = 0.32$). Sixty percent of the women in this sample met either full or partial DSM-IV-TR diagnostic criteria for PTSD. Twenty-one women (52%) reported experiencing at least one stressful life event at T1. Three women (7.5%) had a life stress scale score ≥ 17 . Overall, women indicated a high level of satisfaction with social support at T1.

Insert Table 2 here

Appraisals and coping style

Table 2 also shows participants' appraisals, coping style and their relationship. Women were significantly more likely to appraise the prenatal diagnosis as a threat or loss, rather than

as a challenge ($x^2(2) = 24.62, p < .001$). In terms of secondary appraisals, women were more likely to state that the diagnosis was something which they “had to accept” and “needed to know more about before they could act” rather than “something they could change or do something about” or “hold themselves back from doing what they wanted to do” ($x^2(3) = 75.13, p < .001$).

Participants were most likely to engage in planning, seeking social support for emotional reasons, positive reinterpretation, growth and acceptance, and least likely to engage in restraint coping, turning to religion, denial, mental or behavioural disengagement and alcohol or drugs. There was no significant difference between emotion-focused and problem-focused coping ($z = -.40, ns, r = 0.04$).

Spearman’s Rho correlations revealed a significant relationship between the secondary appraisal, “the situation was one in which you needed to know more before you could act” and problem-focused coping ($r_s[40] = .35, p < .05$). No other primary or secondary appraisals were associated with coping style.

Psychological adjustment

With regards to the time after childbirth, none of the demographic information was correlated with either total HADS score or positive affect. The total score on the LES was positively associated with total HADS score ($r_s[40] = .46, p < .01$). Primary threat ($r_s[40] = .29, p < .05$) and loss appraisals ($r_s[40] = .29, p < .05$) were positively correlated with total HADS score but not with positive affect. Primary challenge appraisals and secondary appraisals were not associated with either total HADS score or positive affect. Problem-focused ($r_s[40] = .41, p < .01$) and emotion-focused coping ($r_s[40] = .47, p < .001$) were positively correlated with positive affect. Emotion-focused coping was negatively correlated with total HADS score ($r_s[40] = -.33, p < .05$) but problem-focused coping was not associated with total HADS score.

Women who were more satisfied with their social support had higher positive affect ($r_s[40] = -.48, p < .001$) and lower total HADS score ($r_s[40] = .41, p < .01$). The number of people providing support was negatively associated with total HADS score ($r_s[40] = -.42, p < .01$) but not associated with positive affect.

Predictors of Psychological Adjustment

In order to determine which variables were associated with adjustment, two hierarchical, stepwise regressions were performed with total HADS score and positive affect at T2 as the outcome variables. Variables were entered in the following order: (1) demographic information (women's age, child's age, sex of child, total HADS score at T1 and positive affect at T1); (2) social support (mean number of people providing support and satisfaction); (3) coping (emotion-focused coping and problem-focused coping) and; (4) primary and secondary appraisals. In order to control for demographic variables and social support, these were entered in earlier blocks.

Stressful life events, women's age, number of people providing support and problem-focused coping significantly explained 57.6% of the variance in total HADS score at T2 ($F(4, 39) = 11.89, p < .001$) (Table 3). As the number of stressful life events and women's age increased by one unit, total HADS score increased by 0.55 and 0.69 respectively. As the number of people providing support and amount of problem-focused coping increased by one unit, the total HADS score decreased by 1.39 and 1.40 respectively.

Satisfaction with social support, emotion-focused and problem-focused coping significantly explained 40.6% of the variance in positive affect at T2 ($F(3, 39) = 8.20, p < .001$) (Table 3). However, satisfaction with social support was no longer a significant predictor of variance by step 2. As the amount of emotion-focused coping and problem-focused coping increased by one unit, the positive affect score increased by 0.40 and 0.20 respectively.

Insert Table 3 here

Discussion

Participants retrospectively reported significant psychological distress and little positive affect between the time of diagnosis and before having their baby, which is in line with previous findings^{7,14,22}. Following childbirth, psychological distress significantly reduced and women experienced more positive affect than following the prenatal diagnosis. This might partly be due to the fact that some of the baby's conditions might have been successfully treated in the meantime. However, levels of anxiety and depression in this sample were still elevated at T2. The high levels of distress in this sample may be a result of caring for a child with significant needs, as parents of children with physical and/or learning disabilities are reported to experience more parenting stress⁴⁵. The PTSD symptom severity and frequency of PTSD diagnosis in this sample suggests many women experience the diagnosis as a trauma.

Although appraisals were correlated with adjustment at T2, they were not associated with coping styles, as would have been predicted by the cognitive model. However, they explained variance in the HADS total score and positive affect at T2. As expected, primary threat and loss appraisals were associated with increased distress, whereas primary challenge appraisals were associated with less distress. This finding is consistent with other research in pregnancy²⁴. The failure of this study to find that appraisals were associated with coping style may be due to the fact that women in this sample did not show a preference for one type of coping, but used a range of strategies.

Participants used both emotion-focused and problem-focused strategies, and both were associated with improved adjustment. The finding that emotion-focused coping was associated with improved adjustment may be anticipated given that the diagnosis was something which

could not be changed and is in line with previous findings²⁵. This study highlights the importance of engaging also in problem-focused coping, and is consistent with other findings that parents need opportunities for active coping following diagnosis¹⁸.

Regression analyses indicated that more stressful life events between the prenatal diagnosis and prior to childbirth were associated with higher levels of psychological distress. Both, satisfaction with social support and the number of people providing support were also associated with adjustment following birth, suggesting that quality and quantity of social support are important²¹. Within the cognitive model of stress and coping, social support is seen as an external resource, and if present, would predict adjustment, which is consistent with the findings of this study.

Results of this study suggest that women's age explained a proportion of the variance in adjustment, with advanced maternal age being associated with increased distress. Advanced maternal age has also been associated with an increased tendency to terminate pregnancies following prenatal diagnosis^{12,13}. The reasons for these findings are not clear and warrant further investigation.

The current study is limited by a relatively small sample size. It included a range of diagnoses, potentially making the findings applicable to women receiving a wide range of different diagnoses. However, aspects specific to certain diagnoses may have been missed as a result. A larger sample would have enabled comparison across conditions with different severity. A response rate of 51.9% may reflect the fact that some women found the questionnaires too long. A majority of the participants were recruited on-line, via voluntary and charitable organisations, which may have led to a biased sample. Women who access these websites may be more inclined to either search for information, or seek social support through on-line support groups, and therefore actively engage in more coping strategies. Furthermore, women were asked to complete questionnaires retrospectively. This may limit the accuracy of

the findings requiring recall. However, long-term recall for pregnancy related events (after 30-40 years) has been shown to be reproducible and accurate and memories of highly arousing emotional events are highly consistent over time^{46,47,48}.

These findings highlight the importance of providing support to women during the remainder of their pregnancy, as they experience significant distress. Women appear to adjust well if they use both emotion- and problem-focused coping, and therefore health professionals need to provide accurate information, give options for taking action, such as being involved in decision-making around the birth and also enquire about women's social support. Following a prenatal diagnosis and for the remainder of their pregnancy, particular attention should be paid to older mothers, those experiencing additional stressful life events and those who are socially isolated, as these women experienced greater distress after childbirth. This is particularly important as maternal distress during pregnancy and after childbirth can have a negative impact on child outcomes^{48,49}. Women may also need support from specialist services as soon as the diagnosis is made. This may help women access accurate information and obtain empathic support. Specialist support may need to be provided to women reporting clinically significant distress and symptoms of PTSD.

Further exploration into differences in coping, appraisals and adjustment in women who receive a prenatal diagnosis compared to women whose children were diagnosed postnatally may be beneficial. It would be useful to investigate whether a prenatal diagnosis offers women an opportunity to adjust prior to delivery, or whether it leads to a period of distress and uncertainty for the remainder of the pregnancy, possibly using a longitudinal design²². Further research is needed to address paternal coping, as well as the needs of other family members, such as siblings and grandparents.

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References

- 1 Park A and Mathews M. Women's decisions about maternal serum screening testing: a qualitative study exploring what they learn and the role prenatal care providers play. *Women Birth* 2009; 22:73-78.
- 2 Reid B, Sinclair M, Barr *et al.* A meta-synthesis of pregnant women's decision-making process with regard to antenatal screening for Down syndrome. *Soc Sci Med* 2009; 69:1561-1573.
- 3 Seror V and Ville Y. Prenatal screening for Down syndrome: women's involvement in decision-making and their attitudes to screening. *Prenat Diagn* 2009; 29:120-128.
- 4 Hyunkyung, C, Van Riper, M and Thoyre, S. Decision making following a prenatal diagnosis of Down syndrome: An integrative review. *J Midwifery Womens Health* 2012; 57:156-164.
- 5 Mitchell LM. Women's experiences of unexpected ultrasound findings. *J Midwifery Womens Health* 2004; 49:228-234.
- 6 Davies V, Gledhill J, McFadyen A *et al.* Psychological outcomes in women undergoing termination of pregnancy for ultrasound-detected fetal anomaly in the first and second trimesters: A pilot study. *Ultrasound Obstet Gynecol* 2005; 25:389-392.
- 7 Hedrick J. The lived experience of pregnancy while carrying a child with a known, nonlethal congenital abnormality. *J Obstet Gynecol Neonatal Nurs* 2004; 34:732-740.
- 8 Kersting A, Dorsch M, Kreulich C *et al.* Trauma and grief 2-7 years after termination of pregnancy because of fetal anomalies - a pilot study. *J Psychosom Obstet Gynaecol* 2005; 26:9-14.

- 9 Mansfield C, Hopfer S and Marteau TM. Termination rates after prenatal diagnosis of down's syndrome, spina bifida, anencephaly, and turner and klinefelter syndromes: A systematic literature review. *Prenat Diagn* 1999; 19:808-812.
- 10 Korenromp MJ, Page-Christiaens GCML, van den Bout J *et al.* A prospective study on parental coping 4 months after termination of pregnancy for fetal anomalies. *Prenat Diagn* 2007; 27:709-716.
- 11 Korenromp MJ, Page-Christiaens GCML, van den Bout J *et al.* Adjustment to termination of pregnancy for fetal anomaly: a longitudinal study in women at 4, 8, and 16 months. *Am J Obstet Gynecol* 2009; 201:160.e161-160.e167.
- 12 Athanasiadis, AP, Polychronou, P, Mikos, T *et al.* Women's expectations and intention to terminate pregnancy in case of abnormal findings at the second trimester level II ultrasound scan. *Fetal Diagn Therapy* 2009; 25:255-263.
- 13 Schechtman K, Gray D, Baty *et al.* Decision-making for termination of pregnancies with fetal anomalies: Analysis of 53,000 pregnancies. *Obstet Gynecol* 2002; 99:216-222.
- 14 Lalor J, Begley CM and Galavan E. Recasting hope: A process of adaptation following fetal anomaly. *Soc Sci Med* 2009; 68:462-472.
- 15 Lalor J, Devane D and Begley CM. Unexpected diagnosis of fetal anomaly: Women's encounters with caregivers. *Birth* 2007; 34:80-88.
- 16 Leuthner SR, Bolger M, Frommelt M *et al.* The impact of abnormal fetal echocardiography on expectant parents' experience of pregnancy: A pilot study. *J Psychosom Obstet Gynaecol* 2003; 24:121-129.
- 17 Pelly D. Women's experiences of fetal abnormality. *BJM* 2003; 11:154-159.
- 18 Graungaard AH and Skov L. Why do we need a diagnosis? A qualitative study of parent's experiences, coping and needs, when the newborn child is severely disabled. *Child Care Hlth Dev* 2006; 33:296-307.

- 19 Kemp J, Davenport M and Pernet A. Antenatally diagnosed surgical anomalies: The psychological effect of parental counselling. *J Pediatr Surg* 1998; 33:1376-1379.
- 20 Tercyak KP, Johnson SB, Roberts SF *et al.* Psychological response to prenatal genetic counselling and amniocentesis. *Patient Educ Couns* 2001; 43:73-84.
- 21 Wilcox BL. Social support, life stress, and psychological adjustment: A test of the buffering hypothesis. *Am J Community Psychol* 1981; 79:371-386.
- 22 Zuskar DM. The psychological impact of prenatal diagnosis on fetal abnormality. *Women and Health* 1987; 12:91-103.
- 23 Lazarus RS and Folkman S. *Stress, Appraisal and Coping*. New York: Springer, 1984.
- 24 Stanton AL, Tennen H, Affleck G *et al.* Cognitive appraisal and adjustment to infertility. *Women and Health* 1999; 17:1-15.
- 25 Brisch KH, Munz D, Bemmerer-Mayer K *et al.* Coping styles of pregnant women after prenatal ultrasound screening for fetal malformation. *J Psychosom Res* 2003; 55:91-97.
- 26 Major B, Richards C, Cooper ML *et al.* Personal resilience, cognitive appraisals and coping: An integrative model of adjustment to abortion. *J Pers Soc Psychol* 1998; 74:735-752.
- 27 Leithner K, Maar A, Fischer-Kern M *et al.* Affective states of women following a prenatal diagnosis: Predictors of a negative psychological outcome. *Ultrasound Obstet Gynecol* 2004; 23:240-246.
- 28 Snaith RP. The hospital anxiety and depression scale. *Health Qual Life Outcomes* 2003; 1:29-31.
- 29 Pallant J and Tennant A. An introduction to the Rasch measurement model: An example using the hospital anxiety and depression scale. *Br J Clin Psychol* 2007; 46:1-18.
- 30 Herrmann, C. International experiences with the hospital anxiety and depression scale: A review of validation data and clinical results. *J Psychosom Res* 1997; 42:17-41.
- 31 Bradburn NM. *The Structure of Psychological Well-Being*. Chicago: Aldine, 1969.

- 32 Powell-Lawton M, Moss M, Kleban MH *et al.* A two-factor model of caregiving appraisal and psychological well-being. *J Gerontol* 1991; 46:181-189.
- 33 Foa E. Posttraumatic Diagnostic Scale. Minneapolis: National Computer Systems, 1996.
- 34 American Psychiatric Association. Diagnostic and statistical manual of mental disorders (4th ed.). Washington DC: American Psychiatric Association, 2000.
- 35 Horsch, A., McManus, F., Kennedy, P *et al.* Anxiety, depressive and posttraumatic stress symptoms in mothers of children with type I diabetes. *J Trauma Stress* 2007; 20:881-891.
- 36 Foa EB, Cashman L, Jaycox L *et al.* The validation of a self-report measure for posttraumatic stress disorder: The posttraumatic diagnostic scale. *Psychol Assess* 1997; 9:445-451.
- 37 Abidin RR. Parenting Stress Index: Professional Manual (3rd ed.). Psychological Assessment Resources, 1990.
- 38 Sarason IG, Sarason, BR, Shearin, EN *et al.* A brief measure of social support: Practical and theoretical implications. *J Soc Pers Relat* 1987; 4:497-510.
- 39 Ferguson E, Matthews G and Cox T. The appraisal of life events (ALE) scale: Reliability and validity. *Br J Health Psychol* 1999; 4:97-116.
- 40 Folkman S, Lazarus RS, Dunkel-Schetter C *et al.* Dynamics of a stressful encounter: Cognitive appraisal, coping and encounter outcomes. *J Pers Soc Psychol* 1986; 50:992-1003.
- 41 Carver CS, Scheier MF and Weintraub KJ. Assessing coping strategies: A theoretically based approach. *J Pers Soc Psychol* 1989; 56:267-283.
- 42 SpSS Inc. Statistical Package for the Social Sciences. Chicago, 2008.
- 43 Perneger TV. What's wrong with Bonferroni adjustments? *Br Med J* 1998; 316:1236-1238.
- 44 Cohen J. A power primer. *Psychol Bull* 1992; 112:155 – 159.

- 45 Hastings RP. Parental stress and behaviour problems of children with developmental disability. *J Intellect Dev Disabil* 2002; 27:149-160.
- 46 Tomeo CA, Rich-Edwards JW, Michels KB *et al.* Reproducibility and validity of maternal recall of pregnancy-related events. *Epidemiology* 1999;774-777.
- 47 Buka SL, Goldstein JM, Sparto E, Tsuang, MT. The retrospective measurement of prenatal and perinatal events: accuracy of maternal recall. *Schizophrenia Res* 2004; 71: 417-426.
- 48 Weymar M, Löw A., Hamm A. Emotional memories are resilient to time: Evidence from the parietal ERP old/new effect. *Human Brain Mapping* 2011; 32: 632-640.
- 49 Cummings EM and Davies PT. Maternal depression and child development. *J Child Psychol Psychiatry* 1993; 35:73-122.
- 50 Teixeira, JMA, Fisk NM and Glover V. Association between maternal anxiety in pregnancy and increased uterine artery resistance index. *Br Med J* 1999; 318:153-157.

Table 1: Demographic information about participants and their children

	Completers (n=40)	Non-completers (n=18)	p-value
Age of mother			.888
Mean	33.18 years	32.94 years	
SD	5.85	5.56	
Disability			.499
Yes	1 (2.5%)	0	
No	39 (97.5%)	40 (100%)	
Ethnic Origin			.466
White British	36 (90%)	17 (94.4%)	
White Danish	1 (2.5%)	0	
Mixed-race Anglo-Indian	1 (2.5%)	0	
Chinese	1 (2.5%)	0	
White South-African	1 (2.5%)	0	
Pakistani	0	1 (5.6%)	
Relationship Status			.930
In a Relationship	38 (95%)	17 (94.4%)	
Single	2 (5%)	1 (5.6%)	
Annual Household income			.903
<10k	2 (5%)	0	
10-20k	4 (10%)	4 (22.2%)	
20-30k	3 (7.5%)	2 (11.1%)	
30-40k	3 (7.5%)	2 (11.1%)	
40-50k	9 (22.5%)	2 (11.1%)	
50-60k	4 (10%)	1 (5.6%)	
60-70k	3 (7.5%)	1 (5.6%)	
70-80k	3 (7.5%)	2 (11.1%)	
80-90k	1 (2.5%)	0	

>90k	4 (10%)	2 (11.1%)	
Prefer not to answer	4 (10%)	2 (11.1%)	
Age of child			.706
Mean	18.25 months	16.86	
<i>SD</i>	10.5	months 15.29	
Sex of child			.600
Female	14 (35%)	6 (42.9%)	
Male	26 (65%)	8 (57.1%)	
Diagnosis of child			.842
Talipes	12 (15%)	6 (42.9%)	
Cleft lip and palate	10 (10%)	3 (21.4%)	
Down's Syndrome	3 (7.5%)	0	
Down's Syndrome and Congenital Heart Defect	2 (5%)	0	
Spina Bifida	2 (5%)	1 (7.1%)	
Spina Bifida and Hydrocephalous	3 (7.5%)	3 (21.4%)	
Cleft Lip	1 (2.5%)	0	
Hydrocephalous	1 (2.5%)	0	
CCAM	1 (2.5%)	0	
Limb Abnormalities and Bowel Condition	1 (2.5%)	0	
Diastatomyelia	1 (2.5%)	0	
Hernia	0	1 (7.1%)	
Exomphalos Fibular Hemimelia			
Stage of pregnancy diagnosis received			.151
2 (5%)		0	
8-14 weeks	31 (77.5%)	14 (100%)	
15-24 weeks	7 (17.5%)	0	
>24 weeks			

Type of screening			.531
Screening	33 (82.5%)	12 (85.7%)	
Diagnostic	5 (12.5%)	1 (7.1%)	
Both	2 (5%)	1 (7.1%)	
		%)	

Key: *SD* = standard deviation

Table 2: Summary of measures of distress, positive affect, psychosocial characteristics, primary and secondary appraisals and coping

	T1 Mean (SD)	T2 Mean (SD)
Depression (HADS)		
Mean (SD)	7.5 (5.61)***	3.7 (4.22)
No. scoring ≥ 8 (%)	18 (45%)	7 (17.5%)
No. scoring ≥ 11 (%)	12 (30%)	2 (5%)
Anxiety (HADS)		
Mean (SD)	11.42(4.98)***	6.80 (4.98)
No. scoring ≥ 8 (%)	30 (75%)	17 (42.5%)
No. scoring ≥ 11 (%)	23 (57.5%)	9 (22.5%)
Total HADS score		
Mean (SD)	18.92(10.12)***	10.5 (8.56)
No. scoring ≥ 12 (%)	28 (70%)	15 (37.5%)
Positive Affect (ABS)		
Mean (SD)	1.95 (1.91)*	3.03 (1.56)
PTSD (PDS)		
Re-experiencing		
Percentage that met DSM-IV-TR criteria	85%	
Mean number of symptoms (SD)	2.2 (1.48)	
Mean symptom severity (SD)	4.05 (3.82)	
Avoidance/Numbing		
Percentage that met DSM-IV-TR criteria	42.5%	
Mean number of symptoms (SD)	2.4 (2.49)	
Mean symptom severity (SD)	4.6 (5.76)	
Hyperarousal		
Percentage that met DSM-IV-TR criteria	57.5%	
Mean number of symptoms (SD)	1.90 (1.58)	
Mean symptom severity (SD)	3.38 (3.39)	
All three symptom clusters		
Percentage that met full DSM-IV-TR criteria	35%	
Percentage that met partial DSM-IV-TR criteria	25%	
Mean PTSD total symptom severity (SD)	12.03 (11.97)	
Social Support (SSQ6)		
Mean Number (SD)	3.19 (2.14)	
Mean satisfaction (SD)	1.85 (1.30)	
Life Events Scale (PSI)		
Mean (SD)	4.33 (6.67)	
No. with at least one event (%)	21 (52.5%)	
No. scoring ≥ 17 (%)	3 (7.5%)	
Primary Appraisals (ALE)		
Threat	2.74 (1.28)	

Loss	2.04 (1.30)
Challenge	1.63 (0.96)
Secondary Appraisals	
Question 1: Change or do something about	0.82 (1.47)
Question 2: Had to accept	4.60 (0.84)
Question 3: Needed to know before you could act	3.28 (2.14)
Question 4: Hold yourself back from doing what you wanted to do	0.92 (1.42)
Coping (COPE)	
<i>Problem-focused coping</i>	2.35 (0.76)
Active Coping	3.02 (0.99)
Planning	2.46 (0.81)
Suppression of Competing Activities	1.98 (0.95)
Restraint Coping	2.78 (0.97)
Seeking Support for Instrumental Reasons	10.09 (2.42)
Mean Total	
<i>Emotion-focused coping</i>	
Seeking Social Support for Emotional Reasons	3.2 (0.84)
Positive Reinterpretation and Growth	3.14 (0.88)
Acceptance	3.29 (0.62)
Turning to Religion	1.64 (9.74)
Denial	1.41 (0.61)
Mean Total	10.14 (1.47)

* $p < .05$, ** $p < .01$, *** $p < .001$

SD = standard deviation, HADS = Hospital Anxiety and Depression Scale, ABS = Affect Balance Scale, PDS = Posttraumatic Diagnostic Scale, SSQ6 = Social Support Questionnaire 6, PSI = Parenting Stress Index, ALE = Appraisal of Life Event Scale, COPE = Coping Operations Preference Enquiry.

Table 3: Hierarchical stepwise regression model for total HADS score and positive affect at T2.

	<i>B</i>	<i>SE B</i>	Sig.
Model for total HADS score at T2			
Stressful life event (PSI)	.55	.15	.001
Women's age	.69	.17	.000
Number of people providing support (SSQ6)	-1.39	.48	.007
Problem-focused coping (COPE)	-1.40	.42	.002
Model for positive affect at T2			
Satisfaction with social support	-.22	.16	.175
Emotion-focused coping	.40	.15	.010
Problem-focused coping	.20	.09	.025

PSI = Parenting Stress Index, SSQ6 = Social Support Questionnaire 6, COPE = Coping Operations Preference Enquiry.