

## The impact of molar pregnancy on psychological symptomatology, sexual function, and quality of life

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### Abstract

**Background.** Molar pregnancy is an unusual complication of pregnancy whereby abnormal placental tissue proliferates in the absence of a fetus. There is usually a protracted follow-up period where pregnancy is contra-indicated. Whilst the medical outcomes of the disease have been well explored, limited data have evaluated the impact on psychological symptomatology, sexual function, and quality of life.

**Methods.** Institutional ethics approval and individual consent were obtained. All women listed on the hospital molar pregnancy register receiving active follow-up ( $n = 102$ ) and a random sample of women who had been registered in the previous 30 years ( $n = 56$ ) were sent a postal survey outlining the purpose of the study and an invitation to participate. Questionnaires included the Hospital Anxiety and Depression Scale (HADS), Satisfaction with Life Scale (SWLS), and Sexual History Form 12 (SHF-12).

**Results.** The response rate was 54%. The key findings were that 60%, 55%, and 18% of women scored  $\geq 10$  on the total HADS,  $\geq 8$  on HADS-A, and  $> 8$  on HADS-D, respectively. The presence of children played a protective role and was associated with significantly better psychological function and quality of life. SWLS were in the lower end of ranges reported for community controls (mean of 23.9). Chemotherapy had an adverse impact on quality of life ratings (SWLS for chemotherapy yes = 21.7, no = 25). Sexual dysfunction was similar to community samples and was independent of age, time since diagnosis, chemotherapy requirement, and presence of children. Qualitative results complemented the quantitative data with similar emotional themes identified as well as issues related to the medical condition, care, and support networks.

**Conclusion.** Women with a molar pregnancy may benefit from a multidisciplinary approach to management that addresses their psychological and sexual needs in addition to medical aspects of care.

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### Introduction

Molar pregnancy is an abnormality of pregnancy and includes a group of interrelated diseases including partial and complete molar pregnancy, invasive mole, placental-site trophoblastic tumour, and choriocarcinoma [1]. Women diagnosed with molar pregnancies have to confront the loss

of a pregnancy and, at the same time, face concerns regarding a potentially life threatening illness [2]. Due to immediate and prolonged stressors, it is hypothesised that women may experience distress psychologically, socially, and sexually in addition to physically [1].

However, limited data have explored the psychological, social, and sexual consequences of molar pregnancy. The lack of data have resulted in clinical care focussing on medical aspects whilst the other impacts of disease have been unintentionally relegated in importance. As molar pregnancies are highly curable with chemotherapy, even in the presence of widespread metastases [3–5], the impact of disease on long-term quality of life is important.

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An advanced search of the biomedical and psychological literature databases from 1966 to 2003 revealed that limited data have evaluated the quality of life, emotional, and sexual impact of molar pregnancy. Women diagnosed with a molar pregnancy undergo the stress of pregnancy loss, a surgical procedure, possible management with chemotherapy, and delays in future childbearing until they have achieved complete gonadotropin remission. Consequent to these immediate and prolonged stressors, psychological, social, and sexual issues may arise. Yet, only five studies have evaluated the psychosocial impact of molar pregnancy [2,6–9] with only two using validated questionnaires [8,9]. The limited data on psychosocial and sexual aspects of molar pregnancy have resulted in clinical care focussing on medical issues whilst the other impacts of disease have been relegated in importance. As survival from this disease is the norm, the impact of psychological and sexual issues may play an important part in the survivor's subsequent quality of life. It is anticipated that women could have unresolved difficulties that persist even beyond the formal follow-up period.

In view of the limited data, we planned to evaluate, using validated questionnaires, the impact of molar pregnancy on quality of life, psychological symptoms, and sexual functioning.

## Methods

A cross-sectional prevalence study was performed. Institutional ethics committee approval and informed patient consent were obtained. Patients registered on the Victorian Molar Pregnancy Register who were receiving follow-up of their disease ( $n = 102$ ) and a random sample of 10% of patients who had received treatment over the past 30 years ( $n = 58$ ) were invited to participate in the study. Women were posted a covering letter, information sheet, consent form, and questionnaire booklet. A reminder letter and questionnaire set was sent if there was no reply within 1 month. Stamped reply-paid envelopes for the separate return of the consent forms and questionnaires were provided.

### Questionnaires

A number of validated questionnaires were included to generate dependent measures of psychological symptoms, quality of life, and sexual function. These dependent measures were then evaluated in light of independent demographic variables. The following questionnaires were included:

**Hospital Anxiety and Depression Scale (HADS):** This questionnaire has been utilised extensively in over 747 clinical studies since it was developed in 1983 and is designed for use amongst patients in non-psychiatric hospital clinics [10–12]. It is divided into an anxiety subscale (HADS-A) and a depression subscale (HADS-D), both consisting of 7 items. HADS is a valid and reliable screening

instrument for assessing separate dimensions of anxiety and depression and detecting cases of both disorders in patients from non-psychiatric hospitals. It gives clinically meaningful results in clinical group comparisons and in correlation studies with various aspects of disease and quality of life [11].

**Satisfaction with Life Scales (SWLS) [13]:** This is a 5-item questionnaire that measures life satisfaction as a cognitive–judgemental process. As individuals are likely to have unique criteria and different standards for a good life, the scale items do not refer to specific life domains such as health or finances, but are global, allowing subjects to integrate and weight these domains in terms of their own values. The items come with a seven-point rating scale, ranging from 'strongly disagree' to 'strongly agree.' The SWLS scores can be interpreted in terms of absolute as well as relative life satisfaction. A score of 20 represents the neutral point on the scale, at which the respondent is about equally satisfied and dissatisfied. Scores of 21–25 represent *slightly satisfied*, 26–30 indicate *satisfied*, whilst 15–19 represent *slightly dissatisfied* and 5–14 are indicative of being *extremely dissatisfied* with life. Normative data for the SWLS are available for diverse populations in addition to some cross-cultural data. The SWLS has favourable psychometric properties including strong internal reliability with a correlation coefficient 0.82 and moderate temporal stability with some long-term consistency of life satisfaction.

**Sexual History Form-12 (SHF-12) [14]:** The SHF is a validated questionnaire to assess sexual behaviour and function. It covers issues such as frequency of sexual activity, sexual function relating to desire, arousal, orgasm, and pain, and overall sexual satisfaction for men and women. A single summary score—global sexual functioning has been generated from the SHF to permit efficient comparison between results from different investigations. It concisely and accurately reflects overall level of sexual functioning. The global sexual functioning score is calculated from 12 of the items. The 12 items are selected to cover various domains of sexual functioning, including frequency of sexual activities, sexual desire, arousal, orgasmic, and erectile abilities. The global functioning score ranges from 0 to 1. Lower scores indicate better functioning. The global sexual functioning scores were found to have high temporal reliability of 0.92 in women and good internal consistencies have also been reported. Cronbach's alpha was 0.50 to 0.70 in female studies [14].

Demographic questions included data relating to age; number of months since diagnosis; number of children with current and previous partner(s), whether or not chemotherapy was required and if yes, the type of chemotherapy.

There was a final section inviting respondent comments for qualitative analysis.

### Focus group

The content of the questionnaires, including the specific inclusion or exclusion of particular questions from the four

questionnaires, was discussed with a focus group of 15 patients (and partners) with a history of a molar pregnancy, who attended an educational update talk, held by one of the authors (RWP). The feedback from the group was incorporated into the selection of questionnaires for the pilot study.

#### *Pilot study*

As a requirement for institutional ethics approval, a pilot study was first undertaken in a random sample of 20 women to assess response rates and acceptability of the questionnaires. The mail-out included a covering letter, information sheet, consent form, and questionnaires. Stamped reply-paid envelopes for the separate return of consent forms and questionnaires were also provided. The questionnaires in the pilot study contained 2 extra questions regarding the appropriateness and importance of the issues discussed in the questionnaires. There were 10 responses, which was a reasonable response rate of 50% to a single mail-out. The findings indicated that the questionnaires were acceptable and relevant. Specifically, amongst the 10 women, 5 found the issues *very appropriate* or *appropriate* and a further 4 stated that they were *neither appropriate nor inappropriate*. Only 1 patient reported that some questions were *inappropriate*. In terms of importance to discuss those issues, 7 of the respondents *agreed* that it was essential, whilst 3 women *neither agreed nor disagreed*. No respondent indicated that the issues were *not essential* or *not very essential*.

As a result of the pilot study, approval to proceed to the definitive project was given by the institutional ethics board, although permission was granted for only a single reminder mail-out for non-responders. As the questionnaires were not altered for the definitive project, responses from the pilot study are included in the definitive study outcomes.

#### *Statistical analysis*

Returned questionnaires were entered onto a database and analysed using Epi Info (Version 2001). As this was a prevalence study, there was no specific comparison group. The aim of the study was to report the extent and magnitude of concerns. However, by using validated questionnaires, data could be compared against normative values from other community populations. Respondents were divided into subgroups based on the following demographic characteristics to study any differences in outcomes. These were age (<35; ≥35 years), time from diagnosis (<18; ≥18 months), chemotherapy required (Yes; No), and presence of children (Yes; No). The cut-off figures for age and time from diagnosis were taken from the overall mean age and median time, respectively. Descriptive statistics were obtained on mood disturbances, sexual functioning, and quality of life to examine the prevalence and magnitude of concerns. Of note,

the cut-off scores for cases and non-cases for the HADS were a total score of 10 and above, HADS-A score of 8 and above, and HADS-D score of 8 and above all of which represented cases [11,12]. Other data were analysed as continuous variables. Analysis of variance (ANOVA) was performed to investigate potential differences between patients using categories of age, time from diagnosis, chemotherapy requirement status, and presence of children. The dependent variables were clustered into three groups (HADS, SWLS, and SHF-12), and each set was employed in the ANOVA.

Qualitative analysis was based upon recurrent themes within respondents' comments in accordance with established methodology [15]. This process involved familiarisation with data to deduce themes followed by 'indexing' sections of comments to identify themes based on key words and message conveyed. Related themes were grouped together under common categories, namely emotions, medical condition, medical care, and social network.

## **Results**

#### *Quantitative data*

Following an initial and reminder mail-out to 160 women, 94 responses were received in total. Of the 94 responses, 16 were found to be of incorrect address and 1 was ineligible due to different pathology. Hence, the response rate was 77/143 (54%). Of note, 3 respondents declined participation. With this, a total of 74 responses were available for analysis. Respondents did not significantly differ from non-respondents in age ( $P = 0.53$ ), time from diagnosis ( $P = 0.67$ ), and presence of metastatic disease or need for chemotherapy ( $P = 0.49$ ).

Table 1 summarises female data against normative values. For total HADS score, 59.5% of respondents scored 10 or more, representing a level of combined psychological symptomatology suggestive of an underlying psychiatric disorder. The majority of this symptomatology fell into the domain of anxiety (55.4%) rather than depressive (17.6%) symptomatology. The mean SWLS score of 23.9 (95%CI 16.6, 31.3) is in the lower end of the normal range of 23–28 reported in several studies of various community populations. A level of sexual dysfunction was noted with participants scoring worse ( $x = 0.52$ ; 95%CI 0.35, 0.69) in SHF-12 compared to scores from community controls ( $x = 0.49$ ).

Table 2 summarises the scores by 2 groups of women aged <35 years and ≥35 years. A trend was noted towards more young women exhibiting levels of psychological symptomatology suggestive of an underlying disorder compared to older women (<35 years = 70.3%; ≥35 years = 48.7%;  $P = 0.06$ ). This was predominantly due to increased levels of anxiety (64.9%) rather than depressive (18.9%) symptomatology. No significant age differences in

Table 1  
Female overall scores

Dependent variable	Score; n = 74	Normative values	
		Cut-off scores for caseness	In general adult population [11]
HADS total score			
Score <10	30 (40.5)	Non-Cases [10–12] <10	Median score = 9
Score ≥10	44 (59.5)	Cases ≥10	Female score ≥10: 44%
HADS-A subscale score			
Score <8	33 (44.6)	Non-Cases [10–12] <8	Median score = 6
Score ≥8	41 (55.4)	Cases ≥8	Female score ≥8: 31%
HADS-D subscale score			
Score <8	61 (82.4)	Non-Cases [10–12] <8	Median score = 3
Score ≥8	13 (17.6)	Cases ≥8	Female score ≥8: 10%
SWLS	23.9 (16.6, 31.3)	Normative range [13]: 23–28 Nurses and health workers: 23.6 (17.5, 29.7) Printing trade workers: 24.2 (18.2, 30.2) Older French–Canadian women: 26.2 (19.6, 32.8)	
SHF-12	0.52 (0.35, 0.69)	Sexually well-functioning women [14]: 0.49 (0.35, 0.63) Women with sexual dysfunction: 0.68 (0.51, 0.85)	

Results for HADS presented as number and percentages.

Results for SWLS and SHF-12 presented as mean and 95% confidence intervals (CI).

satisfaction with life or sexual functioning measures were identified.

Table 3 summarises the impact of time from diagnosis on outcomes. The length of time from diagnosis did not have a

Table 2  
Female scores according to age

Dependent variable	Age <35 years; n = 37	Age ≥35 years; n = 37	P value	Odds ratio (95%CI)
HADS total score				
Score <10	11 (29.7)	19 (51.4)	0.06 <sup>a</sup>	2.49 (0.87, 7.28)
Score ≥10	26 (70.3)	18 (48.7)		
HADS-A score				
Score <8	13 (35.1)	20 (54.1)	0.10 <sup>a</sup>	2.17 (0.77, 6.18)
Score ≥8	24 (64.9)	17 (46.0)		
HADS-D score				
Score <8	30 (81.1)	31 (83.8)	0.76 <sup>a</sup>	1.21 (0.31, 4.67)
Score ≥8	7 (18.9)	6 (16.2)		
SWLS score	24.5 (17.8, 30.9)	23.24 (15.3, 31.2)	0.51 <sup>b</sup>	
SHF-12 score	0.49 (0.34, 0.64)	0.55 (0.36, 0.74)	0.10 <sup>b</sup>	

HADS score presented as number and percentage.

SWLS and SHF scores presented as Mean and 95% Confidence Intervals (CI).

<sup>a</sup> P value determined by Mantel–Haenszel Chi-square test.

<sup>b</sup> P value determined by Student's *t* test.

significant influence on the incidence of cases in HADS total score ( $P = 0.30$ ) and HADS-A ( $P = 0.26$ ). However, there was a trend towards more recently diagnosed women displaying depressive symptomatology (HADS-D: <18 months = 26.7%; ≥18 months = 11.4%;  $P = 0.09$ ). No significant differences in quality of life or sexual functioning scores were found between the 2 groups.

Table 4 summarises the effect of chemotherapy on outcomes. There were no significant differences in psychological symptomatology or sexual function scores between groups. However, there was a trend for patients receiving chemotherapy to have lower quality of life scores (SWLS: chemotherapy yes = 21.7, chemotherapy no = 25.0;  $P = 0.08$ ).

Table 5 summarises the scores of women with and without children. Children were a protective factor for GTD patients. Fewer of the women with children exhibited total HADS score suggestive of an underlying psychological disorder using case criteria ( $P = 0.04$ ), principally due to a reduction in anxiety domains (HADS-A: children = 46.9%, no children = 72%;  $P = 0.04$ ). The presence of children was associated with significantly higher quality of life with SWLS scores of 25.5 and 20.8 respectively for women with and without children ( $P = 0.007$ ). However, SHF-12 scores were similar between the 2 groups ( $P = 0.75$ ).

#### Qualitative data

Forty-nine of the 74 female respondents wrote comments on their molar pregnancy experience. Several themes, including emotional and fertility issues, fear of recurrence, and the positive role of children complemented the quantitative data. Quotes from the respondents can be found in the Appendix A.

Table 3  
Female scores according to time from diagnosis

Dependent variable	Months <18; n = 30	Months ≥18; n = 44	P value	Odds ratio (95%CI)
HADS total score				
Score <10	10 (33.3)	20 (45.5)	0.30 <sup>a</sup>	1.67 (0.57, 4.90)
Score ≥10	20 (66.7)	24 (54.6)		
HADS-A score				
Score <8	11 (36.7)	22 (50)	0.26 <sup>a</sup>	1.73 (0.60, 4.99)
Score ≥8	19 (63.3)	22 (50)		
HADS-D score				
Score <8	22 (73.3)	39 (88.8)	0.09 <sup>a</sup>	2.84 (0.72, 11.60)
Score ≥8	8 (26.7)	5 (11.4)		
SWLS score	22.9 (15.4, 30.5)	24.6 (17.4, 31.8)	0.35 <sup>b</sup>	
SHF-12 score	0.50 (0.32, 0.68)	0.54 (0.37, 0.71)	0.33 <sup>b</sup>	

HADS score presented as number and percentage.

SWLS and SHF scores presented as mean and 95% confidence intervals (CI).

<sup>a</sup> P value determined by Mantel–Haenszel Chi-square test.

<sup>b</sup> P value determined by Student's *t* test.

Table 4  
Female scores according to chemotherapy requirement status

Dependent variable	Chemo-Yes (n = 25)	Chemo-No (n = 49)	P value	Odds ratio (95%CI)
HADS total score				
Score <10	9 (36)	21 (42.9)	0.57 <sup>a</sup>	1.33
Score ≥10	16 (64)	28 (57.1)		(0.44, 4.06)
HADS-A score				
Score <8	11 (44)	22 (44.9)	0.94 <sup>a</sup>	1.04
Score ≥8	14 (56)	27 (55.1)		(0.35, 3.06)
HADS-D score				
Score <8	22 (88)	39 (79.6)	0.37 <sup>a</sup>	0.53
Score ≥8	3 (12)	10 (20.4)		(0.10, 2.44)
SWLS score				
	21.7 (13.9, 29.6)	25.0 (18.2, 31.9)	0.08 <sup>b</sup>	
SHF-12 score				
	0.52 (0.35, 0.69)	0.52 (0.35, 0.69)	0.99 <sup>b</sup>	

HADS score presented as number and percentage.

SWLS and SHF scores presented as mean and 95% confidence intervals (CI).

<sup>a</sup> P value determined by Mantel–Haenszel Chi-square test.

<sup>b</sup> P value determined by Student's *t* test.

### Sadness/depression

Clinically, the range of unhappiness scored by this group of women fell between occasional sadness and clinical depression. Often, they objectified their state of mind as 'depression' by using terms such as 'upset,' 'sad,' and 'depressed.' Most women identified causal reasons for their feelings. The diagnosis of the molar pregnancy was the most commonly stated reason for the onset of depression. Other causes for sadness included involuntary delay with child-bearing and the need for treatment.

After the treatment path for molar pregnancy ceased, earlier feelings still persisted for some women. For others, it became a memory, 'a sad episode' in their lives with depressive symptoms often left undiagnosed for long periods.

### Grief

Grief experienced by the patient related largely to loss of a potential baby. The fact that there was no tangible loss made it more complex.

### Uncertainty

Women were left with major uncertainties, often questioning 'how and why this all happened.' There was apprehension about the future and confusion about the meanings of conflicting information given. Such unclear and residual uncertainties resulted in generalised anxiety states and feelings of loss of control over one's destiny.

### Lost expectations/profound hopelessness

Women expressed extensive feelings of disappointment, lost expectations, and generalised hopelessness over the loss

of an anticipated 'baby.' For some, this loss represented failure, unachieved and possibly now unattainable goals. Low self-esteem and resentment was noted in this group of women especially towards those who had achieved such a goal.

Once active molar pregnancy management had been concluded, persistent fears concerning subsequent pregnancies, fear of recurrence, sex, and unachieved fertility life goals were paramount for those approaching the end of childbearing age.

### Anxiety

Women acknowledged anxiety states with the use of words such as 'stressed,' 'tense,' 'anxious,' 'nervous,' and 'having a nervous breakdown.' Anxiety occurred both around the features and consequences of the disease itself.

For many women, anxiety persisted after completion of treatment and into their next pregnancy. Anxiety was also a result of other emotional responses such as confusion, anticipation, uncertainty, and frustration.

### Shock

Shock came with the unexpected diagnosis of a potentially fatal condition following a period of joyous anticipation. The whole process of molar pregnancy was described as a 'devastating' and traumatic experience.

### Isolation

The feeling of isolation was felt due to the rarity of the disease as well as the general lack of knowledge by both the general public and in particular, health care workers.

Table 5  
Female scores according to presence of children

Dependent variable	Children-Yes; n = 49	Children-No; n = 25	P value	Odds ratio (95%CI)
HADS total score				
Score <10	24 (49.0)	6 (24)	0.04 <sup>a</sup>	0.33
Score ≥10	25 (51.0)	19 (76)		(0.10–1.07)
HADS-A score				
Score <8	26 (53.1)	7 (28)	0.04 <sup>a</sup>	0.34
Score ≥8	23 (46.9)	18 (72)		(0.11–1.08)
HADS-D score				
Score <8	41 (83.67)	20 (80)	0.69 <sup>a</sup>	0.78
Score ≥8	8 (16.33)	5 (20)		(0.20–3.20)
SWLS score				
	25.5 (18.4, 32.7)	20.8 (13.9, 27.6)	0.007 <sup>b</sup>	
SHF-12 score				
	0.52 (0.35, 0.69)	0.53 (0.35, 0.71)	0.75 <sup>b</sup>	

HADS score presented as number and percentage.

SWLS and SHF scores presented as mean and 95% confidence intervals (CI).

<sup>a</sup> P value determined by Mantel–Haenszel Chi-square test.

<sup>b</sup> P value determined by Student's *t* test.

### *Fertility concerns*

Following the loss of a ‘baby,’ women were concerned about future limited opportunities for having children, something they had assumed to be one of life’s entitled fulfillments. Paradoxically, conception became associated with unwelcome fears, anxiety, and panic due to unresolved molar pregnancy concerns.

### *Delay in childbearing*

Women were anxious to get pregnant again to overcome memories associated with the loss of a ‘baby’. However, it was difficult to balance this need for future pregnancies whilst complying with the recommended time frame of contraception. The delay hindered some women from fulfilling their desire to have children, especially those approaching the end of reproductive age.

### *Recurrence*

Fear of a recurrent molar pregnancy was reported before, during, and after subsequent pregnancies. Women were concerned that a second molar pregnancy would have significant emotional impact. Fear was expressed in the forms of ‘worry,’ ‘nervousness,’ and ‘fright.’

### *Concurrent/subsequent medical conditions*

Concurrent and subsequent medical conditions made coping harder, especially with psychological and gynaecological problems leading to the blaming of the other illnesses upon the molar pregnancy.

### *Support group*

Women sought help from the Molar Pregnancy Support Group to access information and gain more understanding of molar pregnancy. Groups functioned as reliable sources of reassurance and venues for learning from people who had gone through similar experiences.

However, some study participants preferred one-on-one counselling and stressed the need for confidentiality. For some, support groups only intensified negative feelings especially when talking to women who were already doing well.

### *Positive role of children*

Women with living healthy children found both motivation and reason to endure and recover from the experience of a molar pregnancy. Children also lessened some of the pain of having lost a ‘baby.’ Bearing children following a molar pregnancy helped with recovery by generating a sense of achievement and gratitude.

## **Discussion**

The key finding was that more than half of the women diagnosed with molar pregnancy exhibited psychological symptomatology suggestive of an underlying psychiatric disorder. Anxiety, manifested through a lack of life focus and exacerbated by the uncertainties and vagrancies of the molar pregnancy, was more commonly expressed than depression. The high incidence of cases amongst molar pregnancy patients could be of clinical significance suggesting the need of psychological intervention in addition to medical aspects of care.

Assuming that psychological turmoil usually lessens with time, we predicted that the impact of molar pregnancy would be more significant during the initial months following diagnosis. A trend towards this pattern was evident leading to the observation that screening and intervention for psychiatric disorders may therefore be best undertaken during the early stages of care when patients are most vulnerable.

We observed that psychological outcomes (as measured by HADS) were found to be independent of chemotherapy treatment. This contradicts previous reports showing intense psychological distress amongst chemotherapy patients [6,8]. Female satisfaction with life ratings (SWLS) were in the lower end of the normal range [13] and were generally lower in patients who had had chemotherapy although the chemotherapy in nearly all circumstances was single agent Methotrexate.

The level of sexual dysfunction (SHF-12 scores) was poorer than that recorded in normative populations [16]. Considering its aetiology, molar pregnancy’s negative effect on sexual functioning could be due to the woman’s association of sex with profound loss of fertility and recurrence of the illness with the attendant threat of mortality.

Previous studies have suggested that women who received chemotherapy [6] and those who still have an active disease status [8] have higher levels of sexual dysfunction. Nevertheless, in this study, the impact of molar pregnancy on sexual functioning was independent of age, time from diagnosis, chemotherapy requirement, and presence of children. This finding reinforces the importance of counselling on the immediate and long-term effects of molar pregnancy on sexual relationships and functioning for all women.

Another key finding was that women who had children at the time of diagnosis or had children after the molar pregnancy had significantly better psychological functioning than women without children particularly in the level of anxiety as reflected in HADS-A scores. This lends support to an earlier study which reported women without children experienced more intense emotions towards pregnancy loss [7] than women with children probably due to a reduction in the stress from future unachieved fertility goals. Whilst the numbers were too small to apply statistical analysis, a number of women intimated that having children to their current partner was an important sign of a woman’s

fulfillment of childbearing needs. If the woman's only pregnancy to her current partner was the molar pregnancy then this lack of relative fertility was a significant stressor.

The presence of children contributed to significantly better quality of life ratings in molar pregnancy patients possibly due to a sense of fulfillment of their fertility goals. Similar findings have been reported in a previous study in which patients with children were more likely to have good to excellent quality of life ratings [9]. The involuntary delay in childbearing experienced by molar pregnancy patients may have a similar impact to that described in women with infertility where a non-tangible loss is experienced [17,18].

Early themes addressed the sudden emotional changes of adjustment. A major initial change was the emotional transition from the joy and healthy anticipation of a live baby to the diagnosis of a potentially fatal disease. Emotional confusion came in the form of shock and disbelief—discovery of the unexpected and appalling news, the harsh end to their fertility goals and dreams. Significant feelings of unexpected depression were described concerning 'the loss' and the need for a potentially long and indefinite medical experience. The findings support the quantitative data that found a trend towards greater depressive symptomatology in women with an acute diagnosis ( $P = 0.09$ ).

Women underwent an experience of grief over the loss of a potential 'baby.' During this period, patients and partners were also forced to absorb a sudden influx of complex medical information usually raising more questions than answers.

Whilst undergoing management, women came to appreciate that the physical route to recovery was not going to be a brief intervention, but rather a lengthy ordeal measuring many months. Emotional issues arose as a result of both the physical treatment and the temporising management course. Frustration was attributed to lack of information and accompanying inadequate care from medical and allied health treatment staff. The physical pain and drain from treatments over a period of time resulted in feelings of anxiety and depression.

Several women acknowledged that attainment of pregnancy was the most effective 'healing device' for overcoming the loss of the 'baby.' However, medically recommended delays in childbearing to allow accurate measurement of gonadotropins contradicted this concept and made short and medium term resolution of grief extremely difficult.

Successful coping was found in the study to be positively influenced by high levels of support obtained from key members of one's social network including partners, family, friends, and health care workers. Molar pregnancy support groups played a role in better patient understanding of the disease as well as providing reassurance and support for patients.

For those with no previous children or limited fertility futures, patients and partners were left with lost hopes and residual fears concerning their inability to fulfil fertility

goals. Some women reported negative thoughts, including feelings of hate, dissatisfaction, and envy, towards those women who had achieved further pregnancies following a molar pregnancy.

Molar pregnancy represents both physically and emotionally a roller-coaster ride through treatments and feelings. Whilst many issues have been identified in this study, individuals usually listed only one or two specific concerns. The study suggests that a multidisciplinary approach to care that addresses emotional, physical, and social issues would bring an improvement to the wellbeing of women with a molar pregnancy. The more specific the approach is in addressing the woman's concerns, the more likely it is that the approach will lead to an effective and efficient outcome.

## Appendix A

Selection of specific comments made in response to questionnaires

### Sadness/depression

"...it (molar pregnancy) made me feel so unhappy and upset all the time." "It (molar pregnancy) caused me great sadness." "My partner and I are still sad that we seem unable to have a child together..." "I occasionally think of my 1st pregnancy (molar) with sadness..." "...I suffered severe depression for 6-12 months, this went undiagnosed until after giving birth to my first baby."

### Grief

"... how to deal with the grief I was experiencing." "And because there wasn't actually a baby lost it was like it didn't matter to any one except me."

### Uncertainty

"One minute you're pregnant and the next, you're told to wait for an unknown amount of time..." "I was fortunate enough to be able to fall pregnant when I wanted to, to then being told that I was, but wasn't pregnant I found very confusing and difficult to process."

### Lost expectations/profound hopelessness

"A very frustrating, disappointing and distressing experience." "... my 'failure' as a woman" "I don't think I will ever have a child..." "how was I supposed to deal with other people's children when I couldn't have one of my own" "I couldn't face sex again." "I fear it (molar pregnancy) may happen again should we try for another child."

### Anxiety

"the tense and wound up feelings are something I have never experienced to this extent..." "...still nervous that something may go wrong" "I was anxious about getting pregnant again after being so sick for so long." "fear and anxiety persisted until the 1st ultrasound (of subsequent pregnancy)." "... they

were very difficult and unpleasant weeks” “The lack of knowledge and availability of reliable information only added to my distress.”

#### Shock

“Totally unexpected and traumatised” “My doctor tried to explain it to me but I was still coming to terms with the word ‘miscarriage’ when the words ‘potential CANCER’ knocked me on my back side.”

#### Isolation

“I don’t think I’ve ever felt more alone. Nobody I knew even knew what a molar pregnancy was.”

#### Fertility Concerns

“...scared it (having a child) will never happen to me.” “At most times I feel as if something could be wrong and I always get the monthly panic which is when I think I could be pregnant”.

#### Delay in Childbearing

“I wonder if we really need to wait a year to try again.” “Not being allowed to fall pregnant was one of the hardest things to hear. Having that choice taken away from me was a struggle.” “...I am getting older and thus afraid I will be unable to have more children”

#### Recurrence

“...I’m actually petrified of getting pregnant again.” “I fear a molar pregnancy happening again and how we would deal with it emotionally.”

#### Concurrent/subsequent medical conditions

“Since the H. M. Pregnancy (1999) I have had 3 early miscarriages. The distress and disappointment continues...” “No periods for 5 years after molar pregnancy; Endometriosis at the age of 40”

#### Support group

“Had it not been for the assistance of the support group... I would have remained in the dark about my condition, and very confused”. “Just telling people has been very helpful and then for people to tell you they’ve gone through the same thing and gone on to have healthy children is reassuring.” “...talking to someone who had a newborn screaming in the background exacerbated the hollowness of my grief.”

#### Positive role of children

“My daughter was my only salvation. I have kept going for her sake.” “Luckily, I have a 2 year old son who gives me so

much joy.” “I am now pregnant with my 2nd and my state of mind is back to normal.” “...we have since been blessed with 2 children.”

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