

# **Investigating the psycho-social impact of NVP- a personal journey.**

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## **Abstract**

The author investigates the impact of hyperemesis gravidarum (HG) on the pregnant woman and her family through a review of the literature and his own experience and research.

Results are discussed in terms of quality of life, physical well-being, mental well-being, impact on families and health care issues.

A number of themes emerge including trauma, guilt, confusion, fear, helplessness, anxiety, depression, loss of control, isolation, relentlessness, olfaction, lack of understanding and disappointment.

It will be concluded that a shift in the provision of health services is required to support women with HG. Practitioners need to move away from the view that hyperemesis gravidarum is just something to be “put up with”. Instead, there needs to be an active management strategy that includes medical and psychological interventions. Health professionals need a better understanding of the condition and recognition that it is a serious illness.

## **Introduction: Authors' personal interest**

I started investigating this condition in 1998 when my wife was in the early stages of pregnancy with our second child. She experienced hyperemesis gravidarum with our first child and this was repeated in this pregnancy. I remember escorting her to hospital and being unable to get her from the car park into the building because she was lying in the car park retching and incontinent. I was deeply shocked to see the humiliation that my wife endured and the distress it caused her.

Because the hospital staff did not know the causes, I began to read about the condition in more detail. I needed to understand what was happening to her and understand the reasons why. I realised from that moment that little was really known that was based on sound research and more should be done to help. It seemed to me that much practice was based on prejudice and misunderstanding.

It is not only the woman's life that is thrown into turmoil by severe NVP: it affects the whole family. It affects the other children in the family. It affects work and relatives and friends. In this respect it is like any other serious illness. If NVP were a recognised illness then people would understand better what the problems are. Even other

women may not empathise, which leads the woman inevitably to feel guilty: other people have coped with pregnancy so why can't she?

The woman may not be able to eat sufficient to maintain energy levels. Women are told by medical practitioners that it does not matter that they are not eating: nevertheless they may become very weak and tired and have depleted energy. The wretchedness of the sickness combines with tiredness so it is not long before the woman becomes depressed and because she is depressed people think she is rejecting the baby. Someone said to my wife "is it because you feel invaded?" Amateur psychoanalysts conclude that she doesn't really want the baby and this can undermine the woman's belief in her own capabilities to carry through the pregnancy.

It is difficult to balance the everyday needs of family life for cooking and cleaning with those of the pregnant woman who cannot tolerate the smell of porridge being made downstairs! As you will see later in this paper, many women report a worsening of symptoms as a result of smells.

Children in the family and other relatives may experience great anxiety about the woman's health. Some women have little support to help them manage their lives at this time. For some women, their symptoms are so severe that a termination of the pregnancy becomes preferable to continuing.

All of this explains why I became interested in the subject. As a Health Psychologist, I was immediately struck by the poor quality of early research and by the shocking ways women had been treated. Take for example the quote from Atlee in 1934:

My routine is as follows: From the moment the patient enters hospital she is denied the solace of the vomit bowl. She is told that, in the event of not being able to control herself, she is to vomit into the bed; and the nurse is instructed to be in no hurry about changing her. I try to see these patients as soon after admission as possible. I assure them very dogmatically that they are going to stop vomiting at once, and that they will leave the hospital perfectly well in a week. I tell them to eat whatever is put before them, and I instruct the nurse in their hearing to give them a fresh meal in 20 minutes if they do vomit. From the beginning they are put on full hospital diet, and their tray is in no way arranged to make them feel that they have digestive capacities other than normal. They are assured that the more they eat the quicker they will get better. (p. 757)

This punitive treatment regime persisted in some institutions until the 1990s (Parker, 1997). Indeed, Steve Lindow, a consultant who

collaborated in my earlier research, relayed an incident from his medical training in the 1970s when he was based in an obstetrics and gynaecology ward. The consultant in charge insisted that women with hyperemesis gravidarum were not to be cared for, were to clean up their own vomit and have regular meals brought to them.

### **Methodology**

I am going to structure this paper by looking at the impact on women in terms of quality of life, physical well-being, mental well-being, effect on families, and perceived support from health care professionals. The data is taken from a variety of published papers. The quotations are examples from my own pilot study into the impact of hyperemesis gravidarum, as well as from reports from women who have contacted me during the last ten years I have been researching this topic. They are included to illustrate the quantitative data as well as to raise some common themes. Naturally, some details have been altered to maintain anonymity. From each heading I will draw out some key themes from the research.

## **1. Quality of life**

There is no doubt that NVP can severely affect the quality of life for the woman. This can include her working life, her social life, and her family life (Attard, Kohli, Coleman, Bradley, Hux, Atanackovic & Torrance, 2002).

The symptoms may be so severe that patients have impaired cognitive function, feel alone and are unable to engage in even the most mundane activities such as watching television or reading (Parker, 1997).

According to the results of O'Brien & Naber's (1992) study, 47% of working women with NVP indicated that job efficiency was reduced, and there was an average of 62 working hours per woman lost.

The woman may feel guilt at losing work, and not all employers are sympathetic to the woman taking time off. One woman stated:

"My employer suggested I was taking advantage of time off and as his wife had not experienced any major sickness during pregnancy he assumed I was 'making it up'."

The quality of life for the woman can be so diminished that it changes her entire life. Patients may become desperate for relief from the symptoms to the extent that they request a termination of pregnancy.

"This illness changed my life, and also led to the worst day of my existence when I terminated my second pregnancy at week 8, after

4 weeks constant, 24 hour vomiting. I begged for help, I went to the hospital and my GP, and in the end my husband drove me to a clinic 60 miles from our home, where I paid to end the life of our baby because I could not take one more day of suffering”

Hyperemesis gravidarum is cited as one of the main reasons that women request termination of pregnancy (Mazzota, Magee, & Koren, 1997). Using data based on case study design, these authors found that 18% of patients reported that they were considering termination and 3.4% actually underwent termination.

From the above, a number of common themes emerge: guilt over sickness and termination: trauma over termination: long-term psychopathology, perspectives of partners, fear and disappointment.

## 2. Physical well-being and nausea.

Women with severe NVP are physically ill. The experience of women with significant NVP has been reported to be as severe as nausea experienced by patients undergoing chemotherapy for cancer (Lacroix, Eason, & Melzack, 2000).

“It is like nothing else I have experienced”. It feels like my whole stomach is coming up”.

“It is relentless”.

“I just wish I could be sick. I am sure it would be better than this constant nausea”.

“I’m not too bad this pregnancy but previous pregnancy I felt sick 24/7 unless I was sleeping or eating.”

“I could write my own book regarding this as I had a horrendous time during my one and only pregnancy with my daughter starting with sickness and my first stint in hospital at 6 weeks I had sickness right through to 8 months and then started with high blood pressure and ended up with eclampsia”.

“I suffered hyperemesis gravidarum sickness with my first child and can honestly say it is the worst illness I have ever suffered in my life”

“any smell makes me want to vomit. Even the smell of Alex (her son)”

Common themes that emerge from the above include: helplessness, relentlessness and heightened olfaction.

### 3. Mental wellbeing

There is increasing research to show that severe NVP has an effect on the mental health for women. Until fairly recently, the received wisdom was that hyperemesis gravidarum was a result of psychopathology. Indeed as recently as 2007 French practitioners still used a psychodynamic explanation for their hyperemesis gravidarum patients. The authors argued that hyperemesis gravidarum is a result of psychic conflicts regarding the pregnancy (Cohen, Ducarme, Neuman, & Uzan, 2007).

However, most recent research supports the notion that poor mental health and psychopathology is a result of the NVP, not a cause (Smith, Crowther, Beilby, & Dandeaux, 2000).

A particularly useful piece of research was by Bozzo, Koren, Nava-Ocampo, & Einarson (2006). They wanted to establish whether women with diagnosed depression (and who were taking anti-depressant medication) prior to pregnancy were more likely to have NVP than a control group of non-depressed women. By considering depression prior to pregnancy, Bozzo *et al.* hoped to determine the direction of this relationship. It can be argued that if the depressed group exhibit more severe NVP than the non-depressed group, then NVP may be a result of the depression. The results showed no significant difference in NVP between the two groups (61% of the depressed group vs. 68% of the non-depressed group). This supported my earlier research that the mental health status of women is affected by the NVP, and not the other way round.

Women with hyperemesis gravidarum have poor mental health. They feel a loss of control, isolation, guilt, confusion and helplessness (Munch, 2002; O'Brien, Evans, & White-McDonald, 2002).

I investigated the psychological health of pregnant women using the General Health Questionnaire (Swallow, Lindow, Masson & Hay, 2005). Our sample comprised all pregnant women who attended antenatal clinics in a six month time period. The data analysis of this investigation revealed a number of important findings. First there was a very high (nearly 50%) psychiatric morbidity according to the GHQ. Second, despite this high psychopathology as measured on the GHQ, most women who were experiencing mild or moderate NVP actually perceived their mental health and physical health as normal, when rated on a visual analogue scale (i.e. they feel good physically and mentally, despite having high GHQ scores). Third, the sub group of women experiencing high levels of NVP had both poor perceived and measured health. The

implications for practice are that women with high levels of NVP should be offered additional support to alleviate their poor mental and physical symptomatology.

Other studies have found a correlation between NVP and depression scores on the Zung Self-rating Depression Scale (Kitamura, Sugawara, Sugawara, Toda, & Shima, 1996), as well a relationship between NVP and stress and helplessness.

“It had a huge detrimental effect on me, particularly I couldn’t focus on work and ultimately I believe contributed to very severe post natal depression which was diagnosed when my baby was 5 weeks old. I believe, with hindsight, my depression started in pregnancy because I felt so awful and was just continually told, never mind, that’s normal”

“I was vomiting up to and over 50 plus times a day, I couldn't even keep water down. I ended up 3 stone lighter at nine months pregnant than I was before I got pregnant. It was never taken seriously by my doctors and I ended up horribly depressed (and at times though I have never told any one this before suicidal, I just wanted it to end) and very weak”.

If methods could be developed that will assist GPs to identify mental health problems during pregnancy, interventions may be put into place that may prevent significant problems later on in pregnancy and beyond.

Themes that emerge from this data include depression, anxiety, stress, loss of control, isolation, confusion, guilt and helplessness.

#### 4. Effect on families

Very little research has looked at the impact on families. I have spoken to relatives of patients who talk in terms of feelings of helplessness, anxiety and stress. The impact on younger children can be particularly distressing. They cannot understand why their mum has to go in and out of hospital, why she is constantly sick and why she cannot do anything anymore. I have even known children to be concerned that their mother is going to die.

There is a body of research that could be undertaken to fully explore the effect of hyperemesis gravidarum on the family.

Parker (1997) found that patients may become isolated and their family become anxious, depressed and fatigued with the additional care and support required.

Families of women with hyperemesis gravidarum experience stress and feel helpless, fearful and anxious. There is a lack of support for them.

#### 5. Health care issues

One of the most common themes in my qualitative research interviewing patients with hyperemesis gravidarum was the feeling that they are not perceived as having a “proper” illness. Other researchers have noted this also. Parker (1997) reported that one of the most common frustrations for patients is the feeling that their sickness is not taken seriously by others: they are unable to feel legitimately sick. There is a lack of information provided or, worse, incorrect information: for example patients are often informed that sickness will be over by week 20, yet in one piece of research (Parker, 1997) 46% of the sample (n=19) were still vomiting after week 20, and 21% vomited to the end of their pregnancy.

“I feel that I could have been treated earlier if my doctor had responded appropriately to my expressed concerns about the severity and impact of the nausea and vomiting I was experiencing.”

“I was just told I had to put up with it”.

“My doctor said it was because I was anxious”.

“Some GPs and midwives whether unwittingly or not act as if the sufferer is simply not trying hard enough to eat and drink and should be grateful that they are less at risk for miscarriage”

“There isn’t any support from public health sector. They don’t understand why you’re in tears and begging for help.....”

“Sometimes I’ve felt that it’s not been taken seriously as an illness and more of some fatty thing pregnant women moan about. Practical advice about how to cope with it and how to take care of older children is non-existent.”

“I had very little medical support and considered abortion and even wished for death at one low point”

The implications are that women who experience NVP require a supportive relationship with their carers. In a study of patient-physician relationships, Munch & Schmitz (2006) identified the need for the physician to be aware of the impact of NVP on the woman

and to develop a trusting relationship with the woman. Physicians perceived by women as more “humanistic” were seen as more positive, understanding and helpful.

Themes that emerge from this include isolation, guilt, confusion, lack of understanding and support.

The themes that have been identified above are summarised in Table 1.

**Table 1:** The impact of hyperemesis gravidarum.

<b>Theme</b>	<b>Description</b>
<b>Isolation</b>	Some women feel isolated and confined to their house, whereas others feel that they would like to be removed from the stresses of having to talk to other family members and friends.
<b>Confusion</b>	Women are confused about why they are experiencing the symptoms. Their symptoms are not explained to them adequately.
<b>Guilt</b>	Women feel guilty – about not being able to prepare food, not being able to play with children, inability to undertake housework, and feeling a burden to partners and family.
<b>Support</b>	Women with a supportive family rate their physical and mental health more positively, despite having significant symptoms of nausea. In contrast, women without a supportive family structure are less positive in their ratings of mental and physical well-being. Women feel unsupported by the health care agencies.
<b>Nausea</b>	It is described as relentless. Most women think that the feelings of nausea are worse than the actual vomiting.
<b>Psychopathology</b>	Women experience significantly higher levels of depression, hopelessness and anxiety.
<b>Food and odours</b>	Women report that they cannot cope with preparing food. Food makes symptoms worse. It is better if food is prepared outside the home to avoid odours.

## Conclusions

To conclude, I would like to finish by listing some of the ways that women feel that they can better be assisted in coping with hyperemesis gravidarum.

The most important point concerns philosophy of care. Practitioners need to move away from the view that hyperemesis gravidarum is just a nuisance and something to be “put up with”. Instead, there needs to be an active management strategy that includes medical and psychological interventions. The psychological intervention must include counselling, especially at a time when the woman is perhaps thinking about aborting the pregnancy. Health professionals need a better understanding of the condition and recognition that it is a serious illness. What women do not need is an attitude that it is “her faults” and that she just has to “keep busy”. Many women have reported to me that they have been patronised.

Other strategies for coping are listed in Table 2.

**Table 2:** Coping strategies for hyperemesis gravidarum patients.

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Visit your GP at an early stage.

Ask your GP to monitor your hydration regularly.

Discuss with your doctor the possibility of taking anti-nausea medication (although many doctors are reluctant to prescribe them)

If taking medication, consider requesting suppositories if you have difficulty keeping oral tablets down.

Avoid odours, especially of frying food. Even faint smells can be troublesome. If possible, do try encouraging your partner to avoid cooking in the house.

Take plenty of rest and relaxation.

Enlist help and support: someone to care for your other children; someone to do the household chores.

Do not feel guilty. It is not your fault.

Avoid stress.

Try to maintain fluid intake, but eat only when and if you feel like it.

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