The impact of online information on health related quality of life amongst women with nausea and vomiting in pregnancy and hyperemesis gravidarum

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ORIGINAL

Objective: To address difficulties women face when attempting to manage nausea and vomiting in pregnancy (NVP) and hyperemesis gravidarum (HG) and to attempt to understand the effectiveness of online information and coping strategies.

Methods: Sixty-four women who were currently experiencing NVP or HG in their pregnancy participated. We obtained baseline scores from the Nausea and Vomiting in Pregnancy Quality of Life (NVPQOL) questionnaire, provided an online information leaflet, and then obtained a second NVPQOL score two weeks later. Total scores of NVPQOL were obtained by summing up 30 items. Qualitative data were obtained regarding knowledge, use and usefulness of strategies provided in the leaflet.

Results: A significant decrease in NVPQOL scores was observed ($p < 0.05$), which indicated an improved quality of life. Participants, who reported use of the suggested coping strategies such as keeping a diary of food intake and their experience, reported it as being helpful in coping with their condition. However, further information was requested regarding possible medications.

Conclusions: It was effective and helpful to provide women experiencing NVP and HG with information and coping strategies.

Practice implications: Online coping information could be a valuable component of NVP and HG interventions that aim to enhance health-related quality of life.

Introduction

Nausea and vomiting, commonly known as morning sickness, is theorised to be caused by the physical and hormonal changes occurring within a woman's body during pregnancy. Nausea and vomiting can occur in up to 80% of all pregnancies; these symptoms usually start around the ninth week of pregnancy and continue to the 20th week (Gadsby *et al* 1993). Approximately 1–2% of women will continue to have these symptoms until they deliver. Their symptoms can range from infrequent morning sickness to constant nausea and vomiting throughout the day (Gadsby *et al* 1993). In a study by Lacroix *et al* it was evident that less than 2% of women experienced nausea during the morning, thus morning sickness is a misnomer, since sickness can occur any time during the day (Lacroix *et al* 2000). It was observed in a study by Weigel & Weigel (1989) that women who were young, non-smokers, less educated and often obese or overweight, had a higher prevalence of experiencing these symptoms. This social demographic predicted a small but significant number of incidences of nausea and vomiting in early pregnancy (Weigel & Weigel 1989). Women who have experienced nausea and vomiting in previous pregnancies are also more susceptible to having similar or the same symptoms again (Jueckstock

et al 2010). Nausea and vomiting in pregnancy (NVP) is defined by the experience of multiple nausea and vomiting episodes throughout the day. The experience of having more than three occurrences of vomiting per day, along with dehydration and weight loss of 5% or 3kgs, or being hospitalised, were all consistent with a diagnosis of a severe form of NVP known as hyperemesis gravidarum (HG) (Jueckstock *et al* 2010).

The direct causes of HG are still unknown, but a hypothesis has linked the condition to *helicobacter pulori* infection, human chronic gondotrophin (HCG), and psychological and hormonal factors (Munch 2000). It is important to be aware that there are other illnesses that can cause NVP which can include hepatitis, pancreatitis, peptic ulceration, gastrointestinal obstruction, thyroid disease and adrenocortical insufficiency (Jueckstock *et al* 2010). Therefore, it is necessary to attempt to exclude other possible causes of nausea and vomiting before diagnosing a patient with HG. Prior to administering a treatment, the seriousness of HG can be measured by the use of questionnaires. One of the available questionnaires is the Pregnancy Unique Quantification of Emesis (PUQE) and Nausea Scoring Index (Parker 1997). The Hyperemesis Impact of Symptoms questionnaire can also be utilised to assess psychosocial aspects of HG along with the physical symptoms (Jueckstock *et al* 2010). Dismissing NVP or HG as an inconsequential feature of pregnancy can lead to serious consequences for both the mother and the fetus (Gadsby *et al* 1993), and can lead to HG being a common cause of women being hospitalised during their first 12 weeks of pregnancy (Munch & Schmitz 2006).

There is a possible division between patients and health care providers' attitudes and views regarding the causes and treatment of NVP and HG. In the case of extreme NVP and HG, the physical and emotional impact this illness has on the patient is often disregarded. It is evident that there is a lack of awareness and understanding of the effects that this condition has on women experiencing frequent nausea and vomiting throughout their pregnancy. The most common difficulty expressed by women in a study by Poursharif *et al* (2008) was their condition not being considered severe by others, which in turn did not allow them to partake in the 'sick' role, due to feelings of guilt and hopelessness (Poursharif *et al* 2008). Meighan & Wood (2005) attempted to generate an understanding of the influence of HG on a patients' '*self-concept, attitude about pregnancy*' because '*her assumption of the maternal role is needed for the provision of optimal nursing care*' (Meighan & Wood 2005). They found that when a diagnosis was received, women remained unsure of the cause since the aetiology remains unknown; as a result women often looked for possible triggers and remedies. Women described HG as '*horrible*', '*miserable*', '*frightening*', and '*like being tortured*' (Meighan & Wood 2005). Some women searched for a way to end their suffering from symptoms, while others attempted to find methods that made the condition easier to tolerate and live with. It was observed that all women expressed feeling a lack of control over their bodies and only thought about their child and its delivery once the symptoms had diminished or stopped (Meighan & Wood 2005). Poursharif *et al* (2008) reported women experiencing psychiatric symptoms such as depression and anxiety and psychosocial consequences including job loss and changes in attitude toward future childbearing (Poursharif *et al* 2008). NVP and HG had an effect on women's ability to carry out daily functions and enjoy a social life, and increased their stress levels. The experience of NVP and HG can have an impact on women's quality of life and has been described as causing social isolation, confusion, guilt, and depression (Munch & Schmitz 2006). Swallow (2010) noted that women felt isolated since there were limitations to when they could leave their home, while others preferred to not engage with others due to finding communication stressful (Swallow 2010). Women were unsure and confused regarding the cause of their symptoms, since their symptoms and condition were not discussed sufficiently by health care providers (Swallow 2010). The experience of NVP and HG limits women's abilities to prepare food, carry out housework, and take care of other children. This results in feelings of guilt and concerns about being a burden on their family and partner (Swallow 2010). All, or a combination of these emotions, can lead to feelings of depression, since women are 'comparing to and despairing of' other women who are not experiencing the same symptoms in their pregnancies.

The current study attempts to address these issues by providing participants with a leaflet from Pregnancy Sickness Support (see Appendix D)**which gives information on communicating with others with similar experiences, explanations of symptoms, and advice on how to re-evaluate feelings of guilt, with the aim of decreasing anxiety and depression and improving quality of life.

Women's satisfaction with the care they receive from health care professionals during their experience with NVP and HG is generally low. Munch & Schmitz (2006) found that where women perceived their physicians as humanistic, and where there was congruence regarding their beliefs about the cause of NVP and HG, there was higher satisfaction with care. Similarly, amongst participants who expressed that their physician implied a psychological cause, a higher level of dissatisfaction with their care was reported (Munch & Schmitz 2006). Unsatisfied patients attempted to find information and support using different means; this leads patients to seek information from websites and online support

groups that fit their needs. This also allows for '*social integration and sharing of knowledge that… may increase involvement in learning and expand patients' understanding of their medical condition*' (Lewis 1999). The current study provided online information (see Appendix D)** regarding symptom tracking, where women were recommended to eat small amounts in order to help reduce nausea, and keep a diary in order to predict symptom-free times in order to help plan and manage food intake. It was suggested that partners could help with filling in the diary, in order to help with the feeling of uselessness. Also informing participants of the Pregnancy Sickness Support group on Facebook allowed women to join in a discussion and receive and provide support from people sharing the same experience.

The current study aimed to address the difficulties women face when attempting to manage NVP and HG. The primary objective was to attempt to understand the effectiveness of providing online information and coping strategies, and also to determine whether this information had a significant effect on health-related quality of life. It also aimed to provide further insight on the health-related quality of life that women experience, and if and how this concept changed over time.

Methods

This study was composed of quantitative methodology and self-report measures. The participants' quality of life was assessed by using the health-related Nausea and Vomiting During Pregnancy Quality of Life (NVPQOL) questionnaire, which is a psychometrically sound self-report measure (∂ = 0.98) used to assess the impact of NVP and HG symptoms on the quality of life of pregnant women. The questionnaire measures women's quality of life during the previous week using 30 items that are categorised in to areas such as physical symptoms, emotions, aggravating factors and limitations (see Appendix A).* Each item on the questionnaire was measured using a 7-point Likert scale where 1 indicated 'none of the time' to 7 'all of the time'. A total score for the NVPQOL questionnaire was obtained by summing up the 30 items (20th item reversed); the scores ranged from 30 to 210, the lower scores indicated a higher quality of life of the participant.

Additional questions were asked regarding the strategies presented in the leaflet, in multiple choice and open-ended format. The questionnaires and information leaflets are designed and formatted using Qualtrics online software. This is a repeated measures design where participants complete the NVPQOL questionnaire and are then prompted to read an information leaflet regarding coping strategies. Two weeks later, by following a link sent to the email address they provided at the beginning of the study, they are requested to complete the NVPQOL again (see Appendix B).* A reminder email was sent to the participants who did not respond one week after the initial email. Using these measures, the study aimed to determine if there were any differences in quality of life reports due to the information provided in the leaflet.

The leaflet provided is composed of four sections and includes general information about the condition, and advice about how to cope. It focuses on the following issues: loneliness and emotions, inability to eat, vitamins, rest, employment and housework, communication strategies, contacting health care professionals and trauma. It also suggests keeping a diary to keep track of symptom-free periods (see Appendix D).**

Women who were experiencing NVP or diagnosed with HG were considered study candidates. Potential participants were recruited by placing a link on the Pregnancy Sickness Support (PSS) charity website (http://www.pregnancysickness support.org.uk/). The link was promoted though the PSS Facebook group and Twitter account. Advertising was also conducted through Facebook groups such as, Hyperemesis Gravidarum Northern Ireland Support Group, Hyperemesis Support Australia, The Student Midwife, Hyperemesis Support Group of Ireland, HG Awareness Day May 15th, Hyperemesis Education and Research (HER) Foundation, Help with Hyperemesis Gravidarum (Excessive Morning Sickness in Pregnancy) and Hyperemesis and NVP Support. A link has also been placed on HER Foundation online discussion forum. The study was also promoted using Twitter by asking groups such as @motherisk, @DietinPregnancy and @HGmoms to share the link with their followers; as well as asking individuals who have shared their experience of NVP or HG on the website to participate. Participants who had completed the initial NVPQOL questionnaire (Time 1), and had read the information leaflet, were sent the NVPQOL questionnaire for a second time two weeks later (Time 2) to the email they provided.

Results

A total of 108 women with a mean age of 31.67 years completed the NVPQOL questionnaire at Time 1, while 64 of those participants completed the questionnaire at Time 2; 64 random scores from Time

* The Nausea and Vomiting During Pregnancy (NVPQOL) questionnaire can be found at: https://tspace.library.utoronto.ca/bitstream/1807/14948/1/MQ54162.pdf

** The information leaflet can be found at: http://www.pregnancysicknesssupport.org.uk/documents/page_pdfs/PL12_Coping_strategies_NEW_2013.pdf

Figure 1: Mean scores of NVPQOL

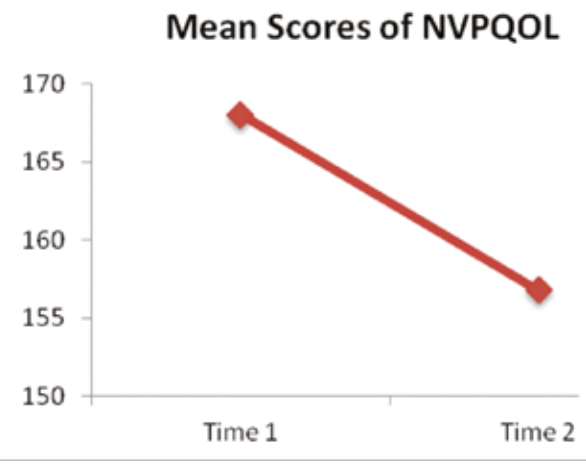
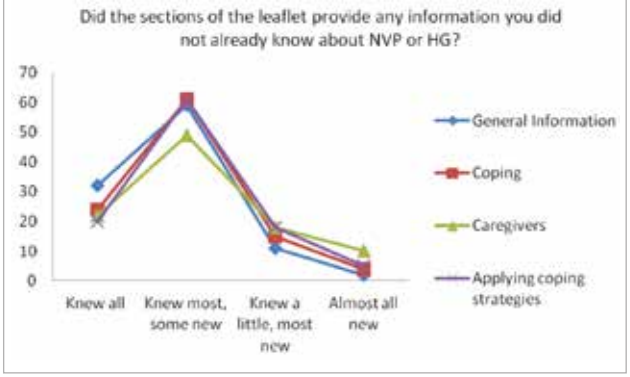


Figure 2



1 were used to compare to Time 2. It was reported that 95.37% of the participants were married or living with a significant other and 88.68% had an education level of a college degree or higher. The mean gestational age was 11.21 weeks, women participated as early as five weeks and as late as 32 weeks. Table 1 shows the mean scores at Time 1 and Time 2 of the NVPQOL questionnaires. The mean statistics NVPQOL score at Time 1 was 168.03 (SD = 27.70) and this demonstrated a decrease to 156.80 (SD = 32.59) at Time 2. Prior to conducting a paired *t*-test, the sampling distribution of the difference scores was verified to be normally distributed in order to satisfy the assumption.

The paired *t*-test indicated a statistically significant difference of mean statistics NVPQOL scores between Time 1 and Time 2, t (63) = 2.27, p = .027

Table 1: Descriptive statistics

	Mean	Std. Deviation	N
Time 1	168.031	27.69733	64
Time 2	156.797	32.585	64

(Table 2). The Cohen's *d* effect size for the difference in the NVPQOL questionnaire scores between Time 1 and Time 2, which was 0.37 indicated that participants at Time 1 scored higher than Time 2, but the difference between Time 1 and Time 2 was small (Fig 1). A within groups analysis of variance (ANOVA) was conducted to determine if the mean scores of both conditions were equal. There was a statistically significant difference between Time 1 and Time 2 on the NVPQOL scores: F (1.63) = 5.15, p <.05 (Table 3). When gestational period was added as a covariate in the analysis, it provided statistically insignificant results F (1.62) = 0.292, p >.05.

Ninety four per cent of participants had not used the Pregnancy Sickness Support group prior to this study, and the few who had reported a using range from less than once a month to daily. As for the information leaflet, 55.96% of the participants claimed to have known most of the information regarding NVP or HG, yet some of the information was new; information regarding caregivers obtained the lowest score (Fig 2). It was reported that 23.84% of the participants knew all of the information provided, mostly the general information and least about applying coping strategies. This was followed by 15.09% of participants who claimed to know a little, yet most was new; this showed a similar pattern in that they were familiar with general information yet found new information regarding caregivers and applying coping strategies. There were very few participants who claimed that almost all the information given was new, yet the information regarding caregivers scored as the least familiar. The helpfulness of the information provided was described by 18.8% to be neutral, 24.57% to be somewhat useful, 15.18% to be very useful and the majority 35.90% of the participants to be useful, general information scoring the highest followed by coping and caregivers and applying coping strategies (Fig 3).

Qualitative data regarding the study and the information leaflet provided was obtained. Content analysis was used to identify the themes aid an understanding of the experience and what the participants thought of the aspects of the study. At Time 1, participants shared that the information provided was helpful, and were thankful for the information regarding the understanding of symptoms and experience. The participants appreciated the coping strategies, the understanding tone of the leaflet, and the support and advice it provided to re-evaluate the feelings of guilt (Table 4).

At Time 2, follow-up questions indicated that the

Table 2: Paired *t*-test results

	Paired differences							
	95 % Confidence interval of the difference							
	Mean	Std. deviation	Std. error mean	Lower	Upper	T	df	Sig. (2 tailed)
Pair 1 Time 1- Time 2	11.23438	39.59387	4.94923	1.34412	21.12463	2.27	63	0.027

majority of participants did not use a food diary to keep track of meals and symptoms. Out of the participants who did use a food diary; 40% reported it to be somewhat useless, while the remaining 60% of participants evenly described the usefulness of food diary to be neutral (20%), somewhat useful (20%) and useful (20%). When asked what the food diary helped with, tracking symptoms and keeping a track of when a good time to eat was scored the highest, yet were reported as neither effective nor ineffective. It was also evident that not many participants used a diary to reflect on their experience, yet for those who did use a diary, 56% reported it to be somewhat useful. When asked to describe how useful or useless the diary was, the themes in the qualitative data demonstrated that the diary was useful (Table 5). It allowed participants to pinpoint the time they were not experiencing nausea or sickness, and helped them to feel better by writing the information down and being positive when they noticed they were having a better day. It was also reported that it aided finding a symptom-free time to eat and drink, as well as helping them to bond with their fetus.

Half of the participants (N = 32) utilised the communication strategies outlined in the leaflet, and the majority of participants reported it was moderately helpful (N = 11) and very helpful (N = 11) for talking to their partners and/or loved ones. Others described that it was somewhat helpful (N = 10) and moderately helpful (N = 9) for talking to health care providers, and a little helpful (N = 7) to somewhat helpful (N = 10) in talking to acquaintances (Fig 4).

Figure 3

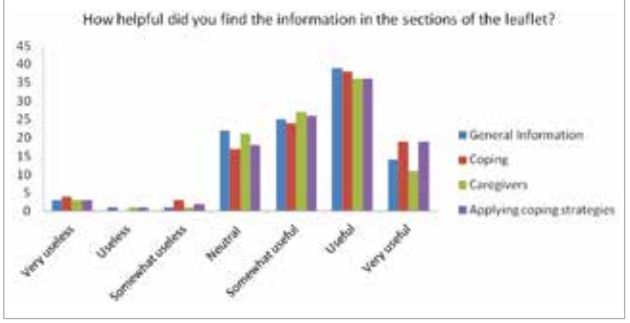
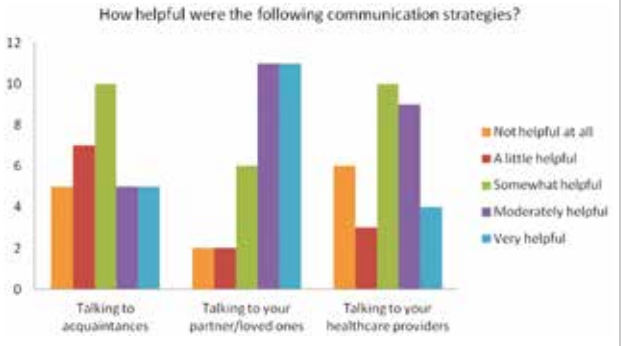


Figure 4



Qualitative data were obtained on the new information that the leaflet provided, that the participants did not know beforehand, and common themes to emerge from the responses were that they found the information to be helpful, increased awareness about how common the condition is,

Table 3: Within groups repeated measures ANOVA

Source		Type III sum of squares	df	Mean square	F	Sig.
NVPQOL	Sphericity assumed	4038.758	1	4038.758	5.153	0.027
	Greenhouse-Geisser	4038.758	1	4038.758	5.153	0.027
	Huynh-Feldt	4038.758	1	4038.758	5.153	0.027
	Lower-bound	4038.758	1	4038.758	5.153	0.027
Error (NVPQOL)	Sphericity assumed	49381.74	63	783.837		
	Greenhouse-Geisser	49381.74	63	783.837		
	Huynh-Feldt	49381.74	63	783.837		
	Lower-bound	49381.74	63	783.837		

Table 4: Do you have any general comments or questions?

Theme	Frequency	Example
Help/helpful/helped	11	'I thought the information was very helpful and reassuring'
Thanks/thankful/thank	11	'The comments on emotional and debilitating side of NVP are the first I've read and were really comforting to see acknowledged, thank you'
Coping/cope	6	'I have been able to cope better this time due to advice and coping mechanisms'
Understanding	6	'I really liked the tone of the leaflet. It was understanding and compassionate'
Advice	4	'I thought the information was helpful and reassuring, especially the coping strategies and advice not to feel guilty'
Guilt	3	'Most important was the part about repeatedly not judging oneself or feeling guilty about coping with HG'
Support	3	'It is nice to know that there is a support group. And many of the feelings described in the leaflet are spot on'

Table 5: Can you describe how it was useful/useless?

Theme	Frequency	Example
Useful	3	'Useful to see that there isn't a pattern with sickness tends to vary every day'
Time	3	'I have been able to find an appropriate time to take my tablets giving me the best time to try and eat and drink'
Better	3	'I scored my nausea out of 10 on a daily basis. This allowed me to see 'better' days where the score may have been slightly lower'
Eat	2	'…giving me the best time to try and eat and drink'
Help	2	'Helped me to 'bond' with the tiny foetus inside me and felt better for having shared the information even though it was only writing it down and wasn't spoken to an actual person'

and learned about the medication options (Table 6). There were also themes in the responses related to information that was missing from the leaflet; these were that women would like further information regarding medications and questions regarding symptoms and risks associated with the condition (Table 7).

Discussion and conclusion

Discussion

There was a statistically significant decrease of NVPQOL scores obtained at Time 1 when compared to the scores at Time 2. Gestational period was not a significant factor when used as a covariate to the NVPQOL scores; this indicates that there was no significant difference in the effect of the leaflet on when it is to be used by participants. The *F*-ratio was greater than one, which expresses that there was less variability between individual participants than between the groups of scores at Time 1 and Time 2. The groups have a significant association with the NVPQOL scores and information leaflet as a dependent variable. At Time 1, participants reported that they knew most of the information provided in the leaflet yet the information regarding caregivers was the least familiar. Despite the high ratings of familiarity with the information, general information, coping strategies, caregivers and applying coping strategies were reported to be helpful. Women reported that they were thankful for the information and the information provided was reassuring, understanding and compassionate. They explained that knowing about the support groups available helped them feel that they were not alone, and it has given them hope knowing other women share similar experiences. This was due to 94% of the participants not being aware of the support groups at the start of the study (Time 1).

At Time 2, participants were asked if they made use of the coping strategy of keeping a food diary. It was evident that the majority of participants did not utilise the diary as a coping strategy, but those who did reported it to be helpful. It was effective in tracking the progress of symptoms and daily food intake; it also allowed for comparison with other days in order to find patterns in symptoms. The communication strategies that were provided were reported to be helpful when used to communicate with partners or loved ones, health care providers and acquaintances. There were two overall themes, the first being that the information leaflet was helpful. This theme was especially evident with the participants that reported using the strategies

Table 6: Was there any information in the leaflet that you did not know before?

Theme	Frequency	Example
Help/helpful/helping	5	'Yes the medication options that were available to me as during my previous pregnancy no one would prescribe anything to help me. I also didn't know that there was a charity set up to help with NVP and that was great to find out'
Aware	3	'I was not aware that my symptoms were so common – so many others had experienced exactly what I was experiencing'
Common	2	'My doctor didn't really take the symptoms especially seriously until I had lost 14 pounds in a week, so being aware that this was quite common is helpful'
Medication	2	'Yes the medication options that were available to me as during my previous pregnancy no one would prescribe anything to help me. I also didn't know that there was a charity set up to help with NVP and that was great to find out'

Table 7: Is there anything that was not included in the leaflet that you want to know about NVP/HG?

Theme	Frequency	Example
Medication/medical treatment	3	'More about safety and efficacy of medications'
Questions	3	'Risk of miscarriage and link to NVP? What the research says on this (if any)'

provided. The second theme was requiring additional information regarding medication. The information leaflet provided information regarding vitamins, yet most participants inquired about the use of alternative medication to help improve symptoms.

Conclusion

The cause of excessive NVP and HG has yet to be determined, yet it is evident that it has an impact on women's physical and psychological well-being. This study has helped provide insight on non-clinical alternatives to coping with this condition, and the usefulness of providing online information to aid women coping with NVP and HG. The findings of this study can help websites and charities improve the information they provide in order to help those who seek health-related information online. This information can also be used by health care providers in improving patient satisfaction with care; openly communicating with patients and not dismissing their symptoms as a regular part of pregnancy could improve patient satisfaction. Using the same coping strategies and techniques might not work for every individual who attempts them, but it is a good starting point before considering other methods or medications. Further research is needed to assess the impact of this information leaflet or other online information over a longer period of time in order to understand its full impact.

Practice implications

Due to participants reporting knowing most of the information suggested, an insight has been gained in to the type of information women are receiving. The majority claimed to be familiar with information regarding their condition and some coping strategies, yet they were less familiar with how the experience of NVP and HG can affect care givers and others around them. Therefore it is important to expand the scope of the information provided to women in order to include family, partners and loved ones, in addition to acquaintances, since the condition could have an effect on others in their social surroundings. Successfully communicating with others could improve understanding of both parties, and aid feelings of isolation and guilt (Swallow 2010). Once this is achieved, it is believed it would decrease the incidence of depression since women would be better informed and equipped and would not compare their pregnancy to other women not experiencing the same symptoms. In addition, 94% of the participants did not know that there were support groups designed especially for women who are experiencing NVP and HG. Participants also described it as comforting to see the emotional and debilitating side of the condition being acknowledged, such as '*feelings described in the leaflet are spot on*'. In addition, online information regarding NVP and HG could be helpful and comforting to women who have recently been diagnosed or have not been well-informed of the condition, its symptoms, and how to cope with it.

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