

Partners in Care – case study

Severe Nausea and Vomiting in Pregnancy (SNVP) – 'Suffering in Silence'

Context

Nausea and vomiting in pregnancy is common, affecting 50-90 percent of women. The more severe form is termed severe nausea and vomiting in early pregnancy (SNVP) affecting about 3-5 percent of women. SNVP is defined by the women and has symptoms that are disabling, with intractable nausea/vomiting leading to dehydration, electrolyte, ketonuria, weight loss (at least 5 percent of pre-pregnancy weight), excluding other diagnosis and nutritional deficiency (ACOG, 2004). The onset is generally in the first trimester at six to eight weeks' gestation, peaking by 12 weeks' gestation and for most women resolving by 20 weeks' gestation (Jarvis, 2011). The physical and emotional impact of SNVP often results in feelings of anxiety and worry about the effect of symptoms on the growing baby. The reality for some women is that they are often not able to undertake their daily activities and 25 percent lose time from housework, 47 percent of women working outside the home feel their job efficiency is reduced and 35 percent lose work time (Arsenault M, Lane C, 2002, & Cochrane, 2015). SNVP is a hidden disorder and can lead to isolation and depression, and can negatively impact on family relationships. Women may have thoughts about elective termination of their pregnancy, and for some this may be a reality to treat the disorder (Arsenault et al 2002, ACOG, 2004).

A team of health care professionals consisting of a lead maternity carer midwife (LMC), maternity quality coordinator, clinical nurse specialist – gynaecology, and a consumer participated in the 2015 Partners in Care co-design programme. They wanted to understand the experiences and support needs of women experiencing SNVP, and their families/whānau, through the development of a co-designed collaborative clinical care pathway.

Aim

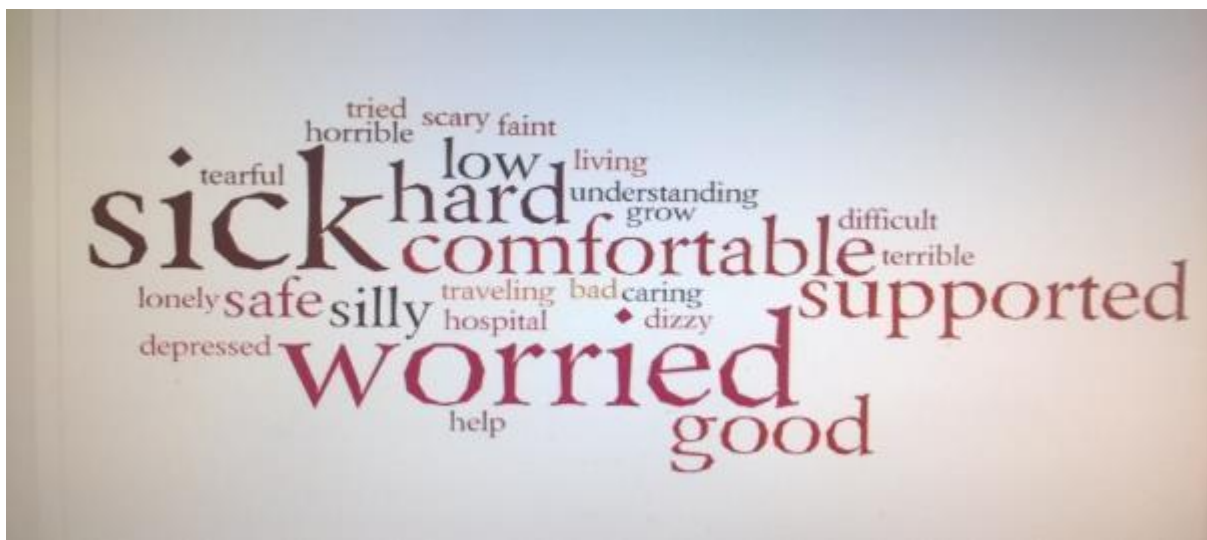
The project aims were as follows:

- Understand the experiences and support needs of women and their families/whānau.
- Understand the experiences of health care providers who support those women and their families/whānau.
- Explore the management and rehydration of women with SNVP in out-of-hospital settings.
- Develop a collaborative care pathway for women with SNVP.
- Explore referral for admission to hospital, for those women who are not eligible for out-of-hospital rehydration/treatment.
- Develop a consumer information leaflet about SNVP.

Capture

We developed an experience based questionnaire (EBQ) to gather information from women with SNVP on how they were feeling, and how intervention, education and information received after seeking care assisted or improved things for them. The EBQ was available in the Gynaecology Assessment and Day Unit (GADU). The LMC midwife emailed it out to clients, and the consumer representative on our project team liaised with NGOs and other community groups to capture stories and experiences from a broader range of women.

Following analysis, the results from the questionnaire were displayed in a wordle. The wordle generated 'word clouds' from the text that we entered and the wordle gives greater significance to words that appear more frequently. 'Sick' and 'worried' were the most commonly used words to describe how the women were feeling. After seeking care and following advice, education and intervention (mostly rehydration and anti-emetics) women self-reported feeling more 'supported and comfortable'.



(www.wordle.net/create)

We carried out in-depth interviews with some of the women, LMC midwives and medical staff to gain their perspective and to explore the option of at-home management and rehydration for women who could be safely managed in the community. Many of the LMC midwives interviewed were supportive of the notion, although in practice this would not be so easy to implement due to the nature of their role; time constraints, cost of consumables and lack of remuneration. Some indicated willingness to undertake home rehydration provided consumables were supplied. It was more challenging to find time to interview medical staff due to the high acuity and workload in the maternity unit; often it was only a brief conversation.

Members of our project group also had conversations with representatives from the Primary Options for Acute Care (POAC) group to explore the development of a clinical collaborative pathway for the management of women suffering with SVNP, which could be safely managed in the community, either at home or in a POAC setting. This would meet the healthcare needs of these women in a timely fashion and provide care closer to home. This

piece of work is progressing well and creates opportunities to improve the primary-secondary interface, and reduce acute demand on hospital services.

A group discussion was held with some registrars and house officers (HSOs) to get their input and participation for the collaborative/co-design planning meetings. Two of the registrars volunteered to participate in the development of the collaborative care pathway. This work is planned to continue after this project concludes.

Understand

Based on the information we gathered during the capture phase from women seen in GADU and in the community, common themes were identified:

- Seeking help too late.
- Afraid and uncomfortable to travel.
- Had follow up/best support from primary caregivers and family,
- Costs and fees were an issue for some women.

This was evident in the findings from the questionnaire and additional narrative. For example, 'I was not aware I could be helped...did not know where to go for help', 'My midwife reached out to me', 'Felt sick, worried and sad' and 'Felt relieved and more comfortable and supported'. These comments were typical of women that were seen in the GADU; they typically presented late and were often quite dehydrated.

The following story shared by one of the women really demonstrates the impact that SNVP had on the woman and her family:

A woman's story:

'It's like having a hangover without the party.'

I didn't have such bad nausea and vomiting in my other pregnancies. I got morning sickness with all of the kids but not like this. I have never lost weight, never ended up in hospital like this. This one was definitely more severe than any of the other ones.

This one started when I got really sick with cellulitis in my leg. The doctor said he did not think it had to do with the leg problem and that is when I found out I was pregnant, and then it just got worse and worse and worse from there. I was only about 3 weeks when I started vomiting. I went to the doctor and they sent me to see the midwives who told me to go back to the GP, and it was just mucking around until yesterday when I was referred to the hospital.

Nausea and vomiting started at 2am every morning and then a week or so later from 4am. From 4am onwards no matter what I did I just continued spewing. I was spewing at least 20 times a day. It made me feel disgusting. It was like my body was shutting down. I could feel it was giving up on me. I have been off work for a couple of weeks. I tried prescription tablets but they did not help at all. I tried so many other things: I'd been to the health food shop and got health pills from them, I tried the Seaband bracelets, I tried ginger, I tried lemon, I tried cranial massage, I tried everything. Nothing was working.

So when I started vomiting I could not go to work and I could not manage the children and my home. My husband had to come home from work and pick up the pieces. It was pretty tough for me and the family. But, today I feel good and feel a lot better in myself since I have had 3 bags of fluid. I am now on a few medications, different vitamins and a needle in my tummy to stop clots because of my dehydration. The plan is to weigh me every day to ensure I am gaining weight again. So I have to eat little bits of food, or try to, but am not sure how long I will stay in. I have to have a scan today.

It was frustrating, really frustrating to go from person to person to get help. In the end I just felt like giving up, suffering, staying at home 'cos I couldn't leave my house without getting sick. It was such an effort to go somewhere and get told to go somewhere else.

Living in a rural area, it would have been helpful if the GP could have prescribed me something and done something locally. It wasn't a problem coming to the hospital but it was a hassle to get someone to look after my daughters late at night and it really stressed them out. Other than that it has been okay. I waited in ED for two and a half hours. They first took me into the ED part and then they put me back outside in the waiting room after giving me a bag of fluids. I was still vomiting at that time. It was horrible sitting out there with a vomit bag. I would just try and hold it in as long as I could. I don't like being in the hospital ward because I don't like the smells of hospital and it doesn't help that I am pregnant. It would be so much better if I didn't have to come into hospital.

I would describe this feeling after vomiting so much as a hangover with no party – just constant...'



The information gathered highlighted the severity of the experience for these women and the impacts, and clearly identified gaps in care delivery such as women's lack of knowledge on when, how and who to seek help from.

Improve through co-design

The themes identified within the capture phase supported the approach we are exploring, which is to offer rehydration and support within the community for those women who can be safely managed in that setting. Through the process of capturing experiences, additional areas for improvement emerged. A high priority was the development of information to provide women with a better understanding of SNVP, and useful information on when and how to seek help, which can lead to earlier intervention and an improvement in their

wellbeing. Given the prevalence of SNVP, women and health professionals need clear guidance about safe and effective interventions (Arsenault et al, 2002 & Cochrane, 2015). The development of a consumer information leaflet goes some way to address this.

We have identified and are co-designing and implementing the following solutions:

1. Development of a consumer information leaflet with consumers. We are planning to trial this with women who have had SNVP and get their feedback before finalising it.
2. Development of a clinical collaborative pathway – POAC

Working as a co-design team – staff and consumers together



Using a co-design approach has added more depth and validity to our process and outcomes. The personal experience of the consumer on our project group, together with data and stories from women with SNVP, has enhanced our understanding of the process that currently exists and where the gaps are, and allowed us to identify areas to improve the experience for women and their families/whānau. One member of the project took the lead in the development of the consumer information leaflet, but at each stage all members of the project group were asked for feedback. By working closely with the consumer in our project group we focused on the language that was used in the information leaflet, ensuring that it was clear and easy to understand

Measure

Engaging with consumers from the beginning of the project has added depth and breadth of knowledge to our project. It helped our project group to understand the experiences of women with SNVP and to develop a consumer information leaflet that will help to improve outcomes. Prior to this project there was no information leaflet available to support woman experiencing SNVP and their families/whānau; now we have one ready to publish.

No information leaflet available = blank canvas

Anxiety & Depression
Ongoing nausea and vomiting can make you feel miserable and depressed. If you are feeling like this speak to your family and midwife/GP as soon as possible so that they can help you with this. Please don't suffer in silence.

Hospital admission
Not all women with SVNP are admitted to hospital, you may be treated in the Gynaecology Assessment Day Unit (GDAU) or the Emergency Department, then discharged home. Occasionally some women with SVNP require a hospital admission for rehydration, anti-sickness medication and rest.

Hospital discharge
Family support is also important in helping treat SNVP. It is vital that family and friends know how you feel so they can help you through this difficult time. They may be able to help especially when you go home by helping to prepare food, doing housework and helping to look after other children to allow you to get some rest.

Helpful Resources
Compendium for a Healthy Pregnancy and Normal Birth by Joan Donley.
ISBN: 0473098776. Available to borrow from the Manawatu Home Birth Association website:
www.homebirthmanawatu.wordpress.com/library
Hyperemesis Education and Research Foundation (HER):
www.helpher.org/mothers/survivalguide-downloads/

After reading this information are there any questions you would like to ask?
List them below and ask your midwife/LMC at your next appointment

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Feedback
If you have any concerns please talk to a member of staff providing your care. They will do their best to address your concerns.
If you are still not satisfied, you can contact our Customer Relations Co-ordinator, phone (06) 350 8980 or (06) 350 8974 or email customer@midcentraldhb.govt.nz
You can also provide feedback to us by completing a "Tell Us What You Think" form located in most services, or using our online feedback form via our website www.midcentraldhb.govt.nz

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Newly developed Patient leaflet SNVP

We plan to do a post change survey and trial the consumer information leaflet with a small focus group. We will also use the EBQ with a small repeat cohort of women, LMC midwives and medical staff, who will have had the opportunity to review and use the consumer information leaflet, and see what they are saying about it now. Anecdotally, one woman's feedback on the draft leaflet suggests that this consumer information leaflet would have helped her with self-management strategies and to recognise the signs and symptoms of SVNP and seek help earlier.

Meeting with LMC midwives and medical staff involved with the care of women during pregnancy and talking to them about our project has increased awareness of the true impact of SNVP on some women. Profiling of the project work through DHB newsletters and Service Improvement meetings has meant that the condition is being talked about more widely. Continued improvements and raising awareness of the condition this will mean that the woman will no longer need to 'suffer in silence'.

Names, email addresses, organisation and DHB of team members

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Inez Schmidt	Consumer	birth@xtra.co.nz	

References

American College of Obstetrics and Gynecology. (2004). *Nausea and Vomiting of Pregnancy*. ACOG Practice Bulletin, 1-12.

Arsenault, M., & Lane, C. (2002). The Management of Nausea and Vomiting of Pregnancy. *Journal of Obstetrics & Gynaecology*, 24 (10), 817-23.

Jarvis, S., & Nelson-Piercy, C. (2011). Management of nausea & vomiting in pregnancy. *British Medical Journal*, 342, 1407-12.

Mella MT. (2011). *Nausea/vomiting of pregnancy and hyperemesis gravidarum. Maternal-fetal Evidence Based Guidelines*. New York City, New York USA: Informa Healthcare, 72-80.

The Cochrane Collaboration. (2013). *Interventions for nausea & vomiting in early pregnancy*. <http://onlinelibrary.wiley.com/doi/10.1002/14651858.CD010607/full>

Other useful resources

1. https://books.google.co.nz/books?id=kOQ4LAAACAAJ&dq=joan+donley's+compendium&hl=en&sa=X&ved=0ahUKEwid3cW0hcTMAhXC3KYKHTDxC_0Q6AEIGjAA
2. <http://onlinelibrary.wiley.com/doi/10.1002/14651858.CD007575.pub4/>
3. HER website: <http://www.helper.org/> and survival guide mentioned