



‘Let’s talk about Miscarriage’

Project team:

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Summary of project

The project idea developed from a growing awareness of the lack of support currently offered to women who experience a miscarriage. The Miscarriage Association (2015) states that one in four pregnancies ends in a miscarriage. This growing awareness, coupled with the fact that care delivery to patients attending the Early Pregnancy Assessment Unit (EPAU) and Gynaecology ward has significantly changed over recent years, and the reorganisation of the Women and Children’s Health Services within Hywel Dda University Health Board (H DUHB) resulting in the centralisation of services (Hywel Dda University Health Board, 2014), all led to the project being very poignant and timely.

In total the project has facilitated 16 events, discussions and meetings to promote ‘Let’s talk about miscarriage’. Ten patient stories were gathered from which three main themes emerged identifying what is important to women about their care:

- **Safe Space** – providing a space which is private, supportive staff
- **Active Listening** – individualised treatment
- **Honest and Open Relationship** – sensitive but factual and truthful, information giving

Values and beliefs work with staff identified that they felt there was a need for formal training and clinical supervision. The project has inspired other services to become involved in miscarriage care such as Ty Cymorth Bereavement Services, individual staff nurses and the H DUHB Patient Experience Manager. This has resulted in several ‘spin off’ projects such as developing the ways patients access patient information, the development of pocket sized signpost cards, the development of miscarriage specific work based competencies and the introduction of clinical supervision.

The stories continue to be re-told through an external national production with a neighbouring Health Board, with the consent and permission of the project participants. This demonstrates that the work of the project will continue and the true power of change lies in the patient stories which can be told time and time again.

Background

The project leader has worked for Hywel Dda University Health Board (HDUHB) for almost three years as a Recovery Nurse in Glangwili General Hospital (GGH). During this time, she was struck by the volume of women affected by miscarriage. The Miscarriage Association (2015) state that one in four pregnancies ends in a miscarriage. The project leader has always had a keen interest in women's health and these aspects prompted the project leader to become the link gynaecology nurse for recovery. Last year the project leader sadly experienced a miscarriage herself. This experience raised awareness of the fact that there was no support offered to women by the hospital. Once at home the project leader conducted an online search to enquire into what support there was. She discovered that at that time in Wales there was nothing available. The search brought up the details of the Miscarriage Association where information on starting up your own miscarriage support group was found, which is what the project leader decided to do.

The project leader started the Carmarthen Miscarriage Support Group in February 2015 offering peer support for anyone affected by loss in pregnancy and since then it has gradually grown and gone from strength to strength. Initial discussions within the miscarriage support group identified stark differences in what information was given to women following miscarriage, sometimes no information was given at all and sometimes no follow up care was offered. In short, the general feedback was that the service currently being offered was 'very patchy'. The group came up with the idea of developing 'pregnancy loss packs', all members of the group were very keen to be involved in the development of the packs and there were instantly many suggestions as to what could be included, such as:

- Sensitive acknowledgement of loss of baby
- Information on what happens next, management options and disposal of products
- Poems
- Scan picture
- Contact details for support – hospital staff, support groups, counselling etc.

Initial discussions with the women of the miscarriage support group identified that when a woman is in that situation, she cannot take information in and/or may not be ready to hear the information. All the women agreed however to have the information in one 'pack', which you are able to take home, would help answer questions raised later on and help them to make the right choices for themselves and their families.

The project leader began thinking about the information gathered from the miscarriage support group and realised that the topic of miscarriage was not really talked about, not even by health professionals directly involved in the care of miscarriage. The project leader came up with the concept of 'Let's talk about Miscarriage', the idea was to develop a project which brought together the health professionals involved in early miscarriage care and patients who have experienced an early miscarriage, so they could begin to talk and share their experiences of miscarriage. By hearing and understanding the lived experience of women who have experienced an early miscarriage, we can begin to use their experiences to change and improve practice.

The setting

Gynaecology Ward: The ward at Glangwili General Hospital in Carmarthen, has undergone considerable change in the past year. The ward is a 16 bed unit with 18 staff members; 1 senior sister, 1 junior sister, 12 staff nurses and 4 healthcare support workers. Staff are committed to delivering holistic, patient centred care to the women. The staff work closely with the Early Pregnancy Assessment Unit Clinical Nurse Specialist and have excellent working relationships with the medical staff. Due to increasing demands on resources the ward also cares for female medical patients. Disciplines involved in care on the ward include medical teams, surgical teams, physiotherapists, occupational therapists and social workers.

Early Pregnancy Assessment Unit (EPAU): The EPAU at Glangwili General Hospital in Carmarthen, is a single nurse run unit providing support to the women of Carmarthenshire and surrounding counties in early pregnancy. The unit list is varied on a day to day basis as the need for input arises. The unit currently operates as a clinic providing a one to one service. The clinical nurse specialist is an autonomous practitioner who can diagnose, discuss management options and arrange admission to the ward as the need arises. Follow up care is also provided for women who have opted to have conservative management of their miscarriage, or medical management of ectopic pregnancies. The unit adheres to NICE (2012) guidelines in the diagnosis of miscarriages and ectopic pregnancies. The unit works closely with the bereavement services who provide support for couples who require formal counselling, but it also provides support to the clinic nurse providing clinical supervision on a monthly basis.

Aims and objectives

Aim: To understand the lived experience of women experiencing an early miscarriage or ectopic pregnancy and to use their experiences to change and improve practice.

Objectives:

1. To identify and engage stakeholders in the project
2. To attract women who have experienced an early miscarriage/ectopic pregnancy to participate in the project by way of advertising for volunteers through the HDUHB media services, Carmarthen Miscarriage Support Group, Gynaecology ward and EPAU
3. To explore the lived experience of the women by using a variety of methods such as interviews, group sessions and questionnaires
4. To explore staff perspectives, values and ethics of caring for a patient who has experienced a miscarriage / ectopic pregnancy
5. To facilitate staff feedback meetings on findings of the initial service evaluation
6. To utilise a practice development framework to implement changes in practice
7. To evaluate the changes in practice and their impact on patient experiences and redesign where necessary

Methods and Approaches

Brief overview

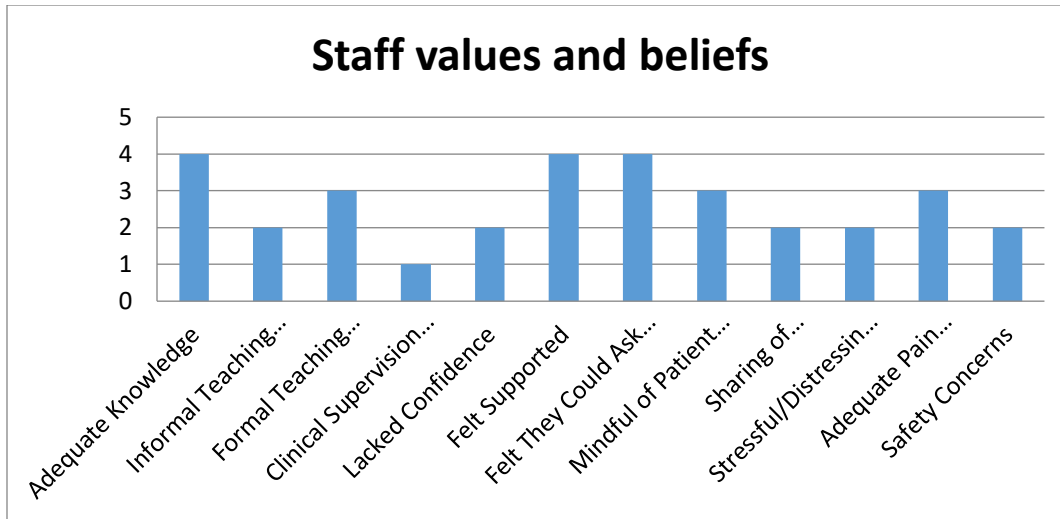
A number of approaches were used in this project to facilitate the changes in practice. These included staff questionnaires, patient free writing exercise, recording of patient stories, staff 'tea party' sessions, staff development sessions, presentation at stakeholder involvement event. See Table 1 below for a timeline of events.

Table 1: Timeline of approaches used	
January 2016	Staff values and beliefs writing exercise
February 2016	Patient story packs issued to patients
February 2016 – Ongoing	Team meeting with key stakeholders - claims, concerns and issues
March 2016	Poster exercise – whole ward participation
April 2016	Patient story theming – ward staff development event
June 2016	Ward tea party
July 2016	Stakeholder participation event – communication of patient stories
August 2016	Staff survey – baseline pre-clinical supervision pilot
September 2016	Present at the Association of Early Pregnancy Units conference – communicate project
September 2016 – February 2017	Clinical supervision 6 month pilot
November 2016	Miscarriage Association visit – patient information
November 2016	Quality and Safety meeting (obstetrics and gynaecology) - communication of patient stories
December 2016	Patient working group
May 2017	Repeat staff survey
May – June 2017	Featuring in Avant Cymru ‘Killer Cells’ production
June 2017	Abertawe Bro Morgannwg University Health Board storytelling for Health international conference – poster and discussion panel

Staff values and beliefs writing exercise

Staff packs were developed containing an invite letter, consent form and a values and beliefs exercise, (see Appendix 1). Help with the development of the packs was sought from the Health Board Patient Experience Manager and Service Improvement Team. Project team members invited all nursing staff members of the gynaecology ward to participate in the exercise. The packs were verbally explained to participants and detailed instructions were written in the pack. Staff members could participate in a free writing exercise at a time convenient to them. Sixteen members of staff were invited to take part in the project out of which 6 completed packs were received back (see Appendix 1a).

The free writing exercises were reviewed by the project team during a team meeting. Common themes were identified and themed as follows:



As a result of these themes, the ward sister identified a need to develop work based competencies, provide clinical supervision and address the clinical environment/ward layout.

Patient story packs issued to patients

Patient packs were developed containing an invite letter, consent form and diary exercise (see Appendix 2). The consent form was adapted from a pre-existing Health Board consent form with the permission of the Patient Experience Manager. The service improvement team advised on service evaluation approval for the project. Patients were invited to participate in person from a range of clinical settings and public settings, including EPAU, the gynaecology ward and the local miscarriage support group. This was mainly done on a face to face, one to one basis, where an informal chat was had about the project. Once patient participants had consented to participate, they were asked to write about their experience of miscarriage. A total of 10 patient stories were collected which were returned either as a hard paper copy or via email.

Team meeting with key stakeholders - claims, concerns and issues

Regular project team meetings were held with key stakeholders invited as appropriate, such as the ward sister and hospital chaplain. Team meeting dates were mutually agreed via email. A claims, concerns and issues exercise (Guba and Lincoln, 1989) was carried out at the beginning of each meeting. Each member was asked to identify a claim (what was working well), a concern about the project and then issues were identified from these to inform action. This enabled the project team to identify questions which provided clear structure, focus, shared vision and development of the project at each stage (see Appendix 3).

Poster exercise – whole ward participation

Five posters were displayed in the day room on the gynaecology ward (see picture right for an example) each with a title question. Participants were invited to comment using separate sticky notes for each poster, the exercise ran for a total of three weeks to encourage whole ward participation and included staff, patients and relatives (Dewing *et al.*, 2014, p.34). Details of the project including contact details for project leader were displayed alongside the posters and ward staff were asked to encourage participation from all attending the ward. It was hoped that a staff workshop could be held in order to feedback the results and carry out more in-depth work exploring staff values and beliefs. However due to ward staffing levels and skill mix it was not possible to release staff to attend an event off the ward. The poster exercise captured the following verbatim:



I believe the purpose of person-centered miscarriage care is:

- *'To help understand what has happened and support the family at this time.'*
- *'To help patient by letting them know what are next steps!'*
- *'To show you see the individual.'*
- *'Support the person.'*
- *'Show staff care.'*
- *'Respecting the person.'*

I believe this purpose can be achieved by:

- *'Having the staff that genuinely care, and having the knowledge to be able to support the family.'*
- *'Knowledge of where to get more help.'*
- *'Staff awareness training.'*
- *'Resources patient leaflets.'*
- *'Having time to care.'*

I believe the factors that help us achieve person-centred miscarriage care are:

- *'Knowledge, empathy, environment and support for the family to move on to the next stage of their grief, and look forward.'*
- *'Staff knowledge.'*
- *'Staff try their best.'*
- *'Information giving.'*
- *'Staff work hard.'*
- *'Time with patients.'*
- *'Staff knowledge experience.'*
- *'To be given more information about the different types of miscarriage.'*
- *'To give help how to move on.'*

I believe the factors that hinder person-centred miscarriage care are:

- *'The environment, dated ward, need an updated quiet space, and not hidden in the corner of the hospital.'*
- *'Lack of resources.'*
- *'Lack of knowledge or experience of staff.'*
- *'Short staffed.'*
- *'Pressures from organisation e.g. bed management.'*

Other values and beliefs I have about person-centred miscarriage care are:

- *'Time to give to the family is so important, this will always be hard for the staff as the unit is very busy and looks dated and clinical. An updated unit would benefit all the staff and families that will be in need of support, as it is now, staff work very hard to give support in hard surroundings.'*
- *'Having a nice quiet space'*

Patient story theming – ward staff development event

The project team felt it would be more appropriate for the patient story theming event to be held away from the hospital in a more neutral location, at the National Botanic Garden Wales. The location was chosen as it provided a positive stimulating environment. Staff from the gynaecology ward were verbally invited to attend the event and a poster was displayed on the ward. The event was attended by 3 staff members, the Health Board Practice and Professional Development Facilitators and the Practice Development Facilitator from FoNS. Each person read out a story while others wrote down key themes on sticky notes which were then put in themes by group discussion. The low uptake from staff was due to staffing resources making it virtually impossible for staff to be released to attend. Recently the ward had experienced a significant number of staff leaving due to retirement and career progression. There was also a number of staff absent due to sickness and maternity leave. This meant that the ward was operating with minimal staff and there was little room for adjustments to off-duty because of the skill mix of experienced and new staff. In hindsight the project leader should have encouraged the staff that were able to participate to feedback findings to staff back on the ward. Feedback from the event was that it was very powerful to hear the stories, but also very emotionally draining due to the nature of the patient stories. The environment enabled reflection and was very peaceful.

Three broad themes were identified:

Safe Space – providing a space which is private, supportive staff

Active Listening – individualised treatment

Honest and Open Relationship – sensitive but factual and truthful, information giving (See appendix 5 for full transcription of themes identified)

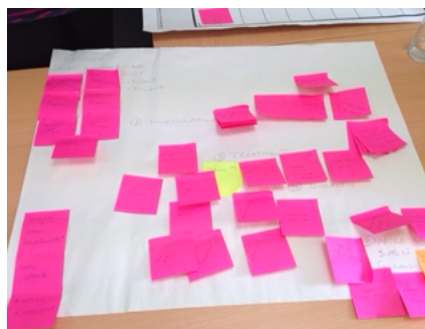


Fig. 1 Patient story theming

The patient stories also contained a lot of positive messages for the ward staff. It was decided at a team meeting that a ward based activity should be held in order to communicate these messages. The project team and key stakeholders ward sister and senior nurses felt it was important to communicate these stories to as many stakeholders as possible.

Ward tea party

It was identified at the patient story event that there was a need to communicate the positive messages back to the ward staff. The project team decided the best way to do this was to provide a tea party on the ward. An interactive feedback tool was developed by the project leader where messages were written under hearts which the staff were then invited to uncover and read. These messages were also placed in small pocket-sized bottles for staff to keep as a reminder of the positive impact they can have on their patients. Despite the fact that this event was held on the ward and advertised, the event was again poorly attended. The project team recognised that more work was needed around understanding the reasons

for lack of staff participation with the project and it was hoped that the proposed clinical supervision pilot would provide an opportunity to explore this.

Fig. 2 Staff were invited to scratch off the heart shapes to reveal positive messages from patients



Stakeholder participation event – communication of patient stories

A stakeholder event was organised in order to communicate the patient stories to a wider stakeholder group. The date was mutually agreed by key stakeholders by use of a conference tool ‘doodle app’ (Doodle, 2016). The aim of the stakeholder event was to hear the patients’ stories, discuss the results of the project so far and to invite stakeholders to make pledges within their own practice. Email invites were sent out to senior management and nurses, health visitor teams, midwife teams and general practitioners within the locality of Hywel Dda University Health Board. This method worked very well as a cascade of email invites occurred with stakeholders sharing the invite. The project team initially invited 30 individuals and 40 people attended. The event attracted people with specialist roles such as a perinatal mental health midwife and flying start health visitors and health care support workers.

The event was held at the National Botanic Gardens again, where a narrator was hired to read the patient stories. This idea was suggested by the Patient Experience Manager who had had experience of working with a charity called Arts Care Gofal Celf. At a team meeting the project team selected five of the patient stories to be retold by the narrator in various locations within the gardens. A sixth patient story, which had been recorded, was played and presented by the Patient Experience Manager. The patient stories were selected in order to give the broadest insight into the service. In order attract as many stakeholders as possible, a guest speaker was invited. The speaker was from the Infertility Network UK – Wales.

After listening to the stories, the Professional and Practice Development Team and the Practice Development Facilitator from FoNS hosted small group discussions and invited stakeholders to make a pledge. The room (part of the Botanical Gardens) was set out informally in a cafe style which facilitated good communication and networking (see Appendix 6 for short quotes taken from some of the patient stories).



Fig 3. Narrator from Arts Care Gofal Celf and stakeholders at the Stakeholder Event Day

Event participants were invited to feedback to the project team about the event and record their pledges to take an action forward. This was collected with the use of flip chart paper and post it notes.

Feedback from the event included:

- *Very beneficial day*
- *Looking forward to receiving follow-up information*
- *Really good event – enable people to share experiences is important – well done*
- *Enjoyed the update and felt it was good to hear people’s personal stories*
- *Very informative session – useful to hear stories and know the services available*
- *Interesting afternoon – thank you*
- *Really enjoyed the afternoon*
- *Very powerful afternoon. Using patient stories to improve patient care – awesome!*
- *Excellent use of patient stories – hard hitting and very powerful!*
- *Good afternoon great location*
- *Session was excellent allowed me to see it from the other side can relate to practice*
- *Powerful stories – information giving important*
- *Excellent session, well balanced, very informative, wonderful location*
- *Multitude of information services, to the point I will have lots to reflect on. Thanks*
- *Wonderful to hear patient stories, to reflect on them and discuss within a group*

Pledges included:

- *Gain Knowledge to be able to provide support – signpost*
- *Understand what people go through no matter what stage of loss*
- *Mapping across wards across sites what information is given out*
- *Staff training – would like more staff to hear the stories*
- *I pledge to listen and provide empathy to patients who experience loss!!*
- *Interesting afternoon – know where to signpost to*

- *Signposting*
- *Be mindful of patients' feelings "in their shoes"*
- *Cascade support information to families – Miscarriage Association*
- *To be more empathetic and communicate effectively with all professionals*
- *To be more aware of my communication with patients and colleagues*
- *I pledge to continue to give feedback*
- *Pledge – pass on information from today to EPU BGH*
- *Signposting to the Miscarriage Association service and the Fertility Network*
- *To continue to listen and support families*
- *Signposting within my work*
- *I pledge to continue to share patient experiences*
- *Pledge to give patients permission to share patient stories to encourage to share and evaluate good practice*
- *My thoughts are being mindful of what I say and do to support families and if I couldn't help find out information e.g. websites etc to help families*
- *Staff training and competencies*
- *My pledge – to use information learned today to support pregnancy loss and infertility*
- *To signpost and use multi-agency services*



Fig. 4 Narrator from Arts Care Gofal Celf and stakeholders at the Stakeholder Event Day

The Association of Early Pregnancy Units National Conference

The project team submitted an abstract to the Association of Early Pregnancy Units National Conference which was accepted. The team wanted to communicate of the project findings to a wider audience. The presentation was well received perhaps because it was the only nurse led project at the conference. The project team was approached at the conference by other teams from all around the country and asked how to start their own project. This provided the opportunity to share the sixth month report of the project.

Miscarriage Association (MA) visit

The MA Chairwoman was invited to meet the project team on the ward to give advice on documentation content and patient information on miscarriage. Also present at the discussions were the HDUHB chaplain and gynaecology ward sister. The discussions were very positive, though development of the documentation is still in progress and beyond the scope of the project. Other discussions included the use of the Miscarriage Association information leaflets. The chair of the MA agreed the wording from the MA leaflets could be used along with acknowledge of the source. The ward sister agreed to recruit one of the ward staff nurses to develop a pocket-sized card with reliable internet links to information. The Patient Experience Manager is currently looking at how patients access HDUHB information throughout all departments. This will continue to be developed after the project completes.

Quality and safety meeting- obstetrics and gynaecology department

The project team were invited to share some of the patient stories at the Quality and Safety meeting for the obstetrics and gynaecology department. This invitation was extended by a member of the Quality and Safety Group who had attended the stakeholder event at the Botanical Gardens Wales. This provided an excellent opportunity to communicate some of the patient stories to senior nursing and medical staff. As a result of this, the senior nurse for women's gynaecology and sexual health pledged to improve the clinical environment where women were cared for. The obstetric consultants and teams found the patient stories very poignant and hard hitting and stated that hearing the stories would definitely inform their future practice.

Patient working group

The aim of the patient working group was to discuss how women access information on miscarriage via the HDUHB and the information given out to women who experience a miscarriage. Invitations were sent out to women who had previously participated in the project and those who had expressed an interest in the project. The session was attended by one person who had previously participated and two new people. Also in attendance was the HDUHB patient experience manager, an EPAU nurse specialist and the project lead. The session proved to be very informative. The women were shown draft documentation, and asked to compare the information leaflets already in use by HDUHB with those of the Miscarriage Association. The women unanimously agreed the Miscarriage Association information leaflets were far more appropriate and sensitive to women's needs.

Clinical supervision

The need for clinical supervision was identified by the staff values and beliefs clarification exercise and also by the three week ward poster exercise. Clinical supervision can be defined as providing a safe environment for clinicians to discuss and reflect on their clinical practice and improve standards of care. The process supports the individual to problem solve, develop knowledge and competence (Royal College of Nursing, 2003). The Bereavement Services were aware of the project because they had been invited to the stakeholder events. The project lead met with the manager of the bereavement services where it was identified that clinical supervision was something the bereavement services could offer the ward nursing staff. It was agreed that clinical supervision would be piloted for a six month period offering 10 members of staff 1hr individual clinical supervision a month. The pilot was funded by Ty Cymorth Bereavement Service and the FoNS Patients First Programme bursary. This highlights the importance of networking and how sometimes it is a matter of talking to the right person at the right time.

The project team designed a staff questionnaire based on the values and beliefs exercise which was issued pre- and post-clinical supervision. The pre-clinical supervision results established a baseline measurement

which enabled the identification of any shift in values and beliefs. The team also decided this would provide a good opportunity to assess the need for the development of a set of specific work based competencies for caring for a woman during a miscarriage. The pre- and post-clinical supervision questionnaires consisted of nine questions each. The pre-clinical supervision questionnaires had 11 respondents whereas the post-clinical supervision questionnaires had eight respondents (three participants were no longer working on the ward). This made it difficult to compare the data pre- and post-clinical supervision, however it was still possible to determine that the clinical supervision had had a positive impact. The results of the questionnaires showed that overall clinical supervision was well received by staff members of all grades on the gynaecology ward. Staff felt more confident in caring for women experiencing a miscarriage, found the work less stressful, felt more supported, felt more able to ask for help and would be more prepared to share their experiences of miscarriage care as part of their continued professional development.

Post-Clinical Supervision Narratives

The true impact of clinical supervision was best captured by narratives from those that attended. Two members of staff volunteered to provide their narratives of receiving clinical supervision for the project evaluation in box below.

Clinical supervision Narrative one

"I participated in 6 sessions of clinical supervision as part of the miscarriage project (supported by the Burdett Trust).

I found these sessions an invaluable outlet in which to discuss my experiences- positive and negative in my relatively new role as a ward sister.

In terms of discussing the (direct) care I provided for women experiencing pregnancy loss, the effect was limited as this is an area in which I feel confident and emotionally equipped to deal with, in the main. However, these sessions enabled me to look at my effectiveness as a leader which is vital in terms of supporting members of my team.

I did find it useful to voice my frustrations and concerns regarding the limitations our poor physical environment places on the quality of care these women experience and the issues we encounter with the medical staff in terms of their lack of experience in this area at times. The impact of the (poor) physical environment in which we care for these women, on their experience at this difficult time, cannot be underestimated and I found supervision a vital outlet to explore my feelings and concerns regarding this and to look to ways to try and improve things despite the constraints we face.

As a new manager I was able to discuss the dynamics of my team and stressors they are experiencing. I found it such a useful process that my manager has agreed for me to continue attending sessions."

Lucy Barratt, Junior Sister gynaecology ward

Clinical Supervision Narrative two

"As part of the miscarriage project I was able to access monthly clinical supervision. Through this process I have been able to reflect on my role as early pregnancy specialist nurse and nurse manager for all of the gynaecology departments. I feel that clinically I can be more compassionate in the care I give patients as I have developed my personal resilience. Despite 26 years' experience in women's health care, the process of breaking bad news to patients epitomises the uniqueness of nursing where

the profession of caring impacts on the personal self. The clinical supervision has taught me to value and look after myself as much as I do others and I have actively encouraged the adoption of this philosophy across my teams.

I have also been able to develop more strategic and efficient ways of working, particularly when developing patient centred services for pregnancy complications. This has resulted in a new health board guideline for the management of ectopic pregnancy and miscarriage, aligning local practice to national standards. I am also introducing the option of home medical management of miscarriage and working towards the provision of manual vacuum aspiration as new treatment options for our local population.

Overall I have found the process extremely empowering and I am very grateful to have had the development opportunity.”

Sarah Rees, senior nurse manager gynaecology

The pilot has been so successful that clinical supervision will now be offered to all managers who work in the EPAUs across the health board sites.

Abertawe Bro Morgannwg University Health Board (ABMU) Storytelling for Health International Conference

An abstract was accepted to present a poster at the conference on the work achieved by the project team so far. The conference facilitated networking with other projects working with patient stories. As a direct result of the ABMU Storytelling for Health International Conference some of the patient stories gathered during the project have been incorporated into an exciting new production ‘Killer Cells’, which is touring South Wales and the West of England during the summer of 2017.

A trailer for the production with audience feedback can be accessed via this weblink:

<https://www.youtube.com/watch?v=VbyEeamhJFU&feature=youtu.be>

Killer Cells, written and directed by Sara Lewis @Killer_Cells, is a story of life, loss, resilience and hope. Inspired by first-hand experiences of miscarriage and ectopic pregnancy, it reveals the hidden heartache of miscarriage, all while emphasising the resilience, optimism and hope of those who experience it.

“... and afterward, some are strong at the broken places.”

Discussion

As the project lead, I believe the project has successfully met the aim set out at the beginning of the project, namely to understand the lived experience of women experiencing an early miscarriage and to use their experiences to change and improve practice. Listening to women and facilitating opportunities to talk about miscarriage has proven to be invaluable in the development of truly women centred care. In total, the project team have facilitated 16 events, discussions and meetings to talk about miscarriage. The staff values and beliefs exercise and whole ward poster exercise identified similar themes which included formal nursing staff training, improvements to clinical environment and open communication. As a result of these themes the ward sister identified a need to develop work based competencies, provide clinical supervision and address the clinical environment/ward layout. The stakeholder event was particularly valuable in that it facilitated the networking of interested professionals, namely the coming together of

services to provide clinical supervision. The results of the clinical supervision demonstrated again that it is good to talk and share experiences.

Sadly, ward participation throughout the project was minimal. After discussing this with the ward sister, it would appear that staff found it difficult to accept help. Staff participation might have been improved if the project lead approached the ward and encouraged ward ownership from the beginning. However, the project's main focus was on facilitating women to share their experiences of miscarriage and use these experiences to improve practice. The project has been successful in opening up communication between service users and service providers, resulting in three key areas in need of review and development as outlined in the recommendations.

As the project lead, this project has been a thoroughly enjoyable and career enhancing experience, one which will stay with me for the rest of my career.

Conclusion

The project lead identified a growing awareness of the lack of support currently offered to women who experience a miscarriage. The aim of the project was to understand the lived experience of women experiencing an early miscarriage and to use their experiences to change and improve practice. Women were invited to contribute towards the project from the EPAU clinic and a local miscarriage support group. In total ten women bravely shared their experiences of miscarriage. These experiences were shared at various stakeholder events and were a powerful insight into the feelings and emotions of such an experience but also gave insight for practitioners into what they could do to make the experience less traumatic. Some of these stories have been shared in a theatre and dance production. The project has mostly enabled a more open dialogue around caring for women in miscarriage and work is ongoing to improve the environment, patient information and nursing competencies.

Recommendations

The project will forward the following recommendation to the HDUHB Nursing Support Team;

- Follow up how patients are provided with and access health board patient information
- Follow up production of pocket sized patient information signpost cards
- Follow up the need for work specific competencies

Acknowledgements

The brave women who participated in the project
All the staff on Picton ward, Glangwili General Hospital
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Resources

Arts Care Gofal Celf, Ground Floor, 24 King Street, Carmarthen, SA31 1BS. Tel. 01267243815 email info@acgc.co.uk website www.acgc.co.uk

Avant Cymru <http://avant.cymru/>

Killer Cells production https://twitter.com/killer_cells

Appendix 1: Example of staff invite letter and consent form

STAFF CONSENT FORM

This form is to give my agreement to share my experiences of delivering miscarriage care and support. I have been given information about what will happen. I have been able to ask questions about the things that I do not understand and believe that they have been answered to my satisfaction.

Please tick yes or no if you are happy with the statements.

	YES	NO
My experiences will be documented and used to improve health services in the future.		
I am under no obligation to share my experiences and I can change my mind at any time, even after I have shared my experiences, without giving a reason, and this will not affect my role any way any.		
If I identify any issues that cause concern for patient safety they will need to be looked at by the organisation.		
Hywel Dda University Health Board might need to contact me again about my experiences and I am happy for them to do so.		
Some of the words that I say may be used in reports as quotes but my experiences will be treated in confidence and my personal details will not appear in any report.		
I am happy for my name to be used in conjunction with my experiences which I understand will make me identifiable.		
You may want to use some of the data documented for training purposes and I am happy for you to do so.		
I am happy for a photograph of me to be taken and for it to used in conjunction with experiences of miscarriage care and support		
My story might be shared with other NHS and partner organisations so that they can learn too and I am happy for this to happen.		
I freely agree to share my experiences of delivering miscarriage care and support.		

Staff/carer signature:	
Date:	
Name (PLEASE PRINT):	
Project Staff signature:	
Date:	
Name (PLEASE PRINT):	
Job title:	

Standard invite letter issued to patients and staff

PROJECT PARTICIPATION INVITE

Dear {insert name}

I am writing to you to invite you to participate in an exciting new service evaluation project *Patients First Programme* which is funded by the Foundation of Nursing Studies (FoNs) and Brudett Trust for Nursing.

The Foundation of Nursing studies (FoNs) and Burdett Trust are two London based institutions who support and fund nurse development and studies. Every year they invite nurse led teams to apply to the programme with ideas to improve practice with a focus on patients. The programme takes on 10 initiatives throughout the UK each year and this year Hywel Dda University Health Board has proudly gained two places, one of which is the project 'Let's talk about miscarriage'.

The aim of the project is to gather patient stories of miscarriage and staff beliefs and values held around delivering care and information to women who have experienced miscarriage. The project will run for eighteen months during which time the goal of the project is to identify and develop the needs of care and support given to women and their families during and after miscarriage.

The information gathered during the project will be used to identify service needs and may be shared with other NHS and partner organisations so that they can learn. The findings and outcome of the project will be presented at a celebratory conference for Nurse Innovation. You will be regularly informed of the project's progress throughout the duration of the project via email or letter.

Yours sincerely

Rachel Whittal-Williams, Project Leader

Appendix 1a: Completed staff values and beliefs writing exercise

I believe the ultimate purpose of <u>Miscarriage</u> <u>management</u> is: <u>management</u> To give the patient the best care and a good experience out of a bad circumstance.
I believe this purpose can be achieved by: Identifying staff & the patients needs of miscarriage management
I believe the factors that help us achieve this purpose are: Talking to patient that have gone through this experience
I believe the factors that hinder us from achieving this purpose are: lack of time to spend with patient To give them the care that they require
Other values and beliefs I consider important in relation to _____ are:

I believe the ultimate purpose of <u>Miscarriage</u> <u>support</u> is: <u>support</u> to help patients through what can be a very difficult period in their life. Good support at this time can make the difference to their memories of the event.
I believe this purpose can be achieved by: Compassion, listening to what patients actually want, being patient, giving only information that they either want or absolutely need.
I believe the factors that help us achieve this purpose are: Developing a caring culture within wards and departments and using things such as keepsake boxes.
I believe the factors that hinder us from achieving this purpose are: Being too rushed/ understaffed.
Other values and beliefs I consider important in relation to _____ are:

I believe the ultimate purpose of <u>Miscarriage</u> <u>management</u> is: <u>management</u> is to provide holistic care to the client a hr. Partner.
I believe this purpose can be achieved by: <u>Emotional support</u> . Communicate, ie keeping them fully informed what to expect. adequate pain relief.
I believe the factors that help us achieve this purpose are: <u>emotional support</u> after leaving the hospital.
I believe the factors that hinder us from achieving this purpose are: <u>shortage of staff</u> . We are very often unable to commence the treatment as the policy states that a venflon is needed. Very often there is no one available to carry out this procedure. the client is advised to come in early few hours later treatment has.
Other values and beliefs I consider important in relation to _____ are:

I believe the ultimate purpose of <u>Miscarriage</u> <u>management</u> is to <u>management</u> provide a sensitive, supportive environment where women are treated with dignity and respect when their pregnancy fails. options should be explained and discussed with the woman & family and her choices respected. Staff should be a key word
I believe this purpose can be achieved by: <u>good communication</u> , good knowledge base, including awareness of different types of management of miscarriage sensitivity, especially when breaking the bad news, allowing the woman time, especially when deciding how she wants the miscarriage managed
I believe the factors that help us achieve this purpose are: <u>good Liaison</u> between the different agencies involved. keeping the woman informed at all times particularly what to expect before, during and after the various procedures (including expectant management).
I believe the factors that hinder us from achieving this purpose are: <u>shortage of staff</u> Time shortage due to heavy workload. Lack of privacy on ward, particularly when cubicles are unavailable. Lack of empathy.
Other values and beliefs I consider important in relation to _____ are:

I believe the ultimate purpose of <u>Miscarriage</u> <u>is</u> : <u>to try to help</u> . <u>is</u> the patient get through such a traumatic event by being sensitive to their feelings & allowing them space & time to grieve.
I believe this purpose can be achieved by: <u>Empathy</u> & sufficient pain + Relief. + Awareness of different types of miscarriage management.
I believe the factors that help us achieve this purpose are: <u>By the patient being</u> well informed & also by taking into account the feelings of the husband or partner
I believe the factors that hinder us from achieving this purpose are: <u>shortage of staff</u> lack of space & lack of knowledge.
Other values and beliefs I consider important in relation to _____ are:

Use the material you collect on here to take to a group discussion.
not been commenced. due to the fact there is no venflon, and at present the kept. cool. has during the night. due to the shortage of beds.

Appendix 2
Patient consent form



PATIENT STORY CONSENT FORM

This form is to give my agreement as a patient to tell my story about my experience of miscarriage care. I have been given information about what will happen. I have been able to ask questions about the things that I do not understand and believe that they have been answered to my satisfaction.

Please tick yes or no if you are happy with the statements.

	YES	NO
My story will be digitally recorded and used to improve health services in the future.		
I am under no obligation to tell my story and I can change my mind at any time, even after I have told my story, without giving a reason, and this will not affect in any way any future care that I or my relatives may need.		
If I raise any issues that cause concern for patient safety I accept they will need to be looked at by the organisation.		
Hywel Dda Health Board might need to contact me again about this story and I am happy for them to do so.		
Some of the words that I say may be used in reports as quotes but my story will be treated in confidence and my personal details will not appear in any report.		
I am happy for my name to be used in conjunction with my story which I understand will make me identifiable.		
You may want to use some of the audio recording for training purposes and I am happy for you to do so.		
My story might be shared with other NHS and partner organisations so that they can learn too and I am happy for this to happen.		
I freely agree to tell my story about my experience.		

Patient signature:	
Date:	
Name (PLEASE PRINT):	
Staff signature:	
Date:	
Name (PLEASE PRINT):	
Job title:	

Office use: story reference code

Patient Diary free writing exercise



GIG
CYMRU
NHS
WALES

Bwrdd Iechyd Prifysgol
Hywel Dda
University Health Board

PATIENT DIARY

Please write an account of your experience of miscarriage. Try and think about all aspects of care, how you felt and how others made you feel. Please use the following questions as a prompt, however you are free to write whatever you feel is appropriate, and answer as open and as honestly as you can.

- Tell us about whether you knew what was happening?
- Tell us about your journey to hospital, did you contact your GP or midwife, go directly to hospital, come in via Accident and Emergency department?
- Tell us about the information you received?
- Tell us about the support you received from healthcare workers e.g. doctor, nurse, healthcare assistant?

Appendix 3: Project team claims, concerns and issues

A template for stakeholders' views: Claims, Concerns and Issues

CLAIMS: What positive statements would I make about

Nice to have patient stories -
will be interesting to find their
experiences through system -
ability to change practice on the
basis of their experiences - will
have hard experiences to give to
management.

CONCERNS: What are my concerns about

Time restraints
Staffing issues, many new
members of staff who are
inexperienced in this environment.

ISSUES: What questions do I have about

Talk to each other!! keep each
other up to date.

Participants' resources, Practice Development School, London: International Practice Development Collaborative (unpublished work taken from Guba and Lincoln, 1989). A more detailed account of Guba & Lincoln's work on Fourth Generation Evaluation (from which Claims, Concerns and Issues are derived) can be found in Chapter 9 of McCormack et al. (2013).

A template for stakeholders' views: Claims, Concerns and Issues

CLAIMS: What positive statements would I make about

Opportunity to develop practice
and the care experienced by
patients.
Increase awareness of experience
of message - to staff, patients
and relatives.

CONCERNS: What are my concerns about

- Staffing: releasing people to participate
- time constraints

ISSUES: What questions do I have about

Participants' resources, Practice Development School, London: International Practice Development Collaborative (unpublished work taken from Guba and Lincoln, 1989). A more detailed account of Guba & Lincoln's work on Fourth Generation Evaluation (from which Claims, Concerns and Issues are derived) can be found in Chapter 9 of McCormack et al. (2013).

Appendix 4 patient story themes as identified from listening to the stories

Session was attended by Project Team Leader, one ward staff nurse (also a member of the project team), one Ward HCSW, 2 Professional and Practice Facilitators GGH and WGH and FoNs Professional and Practice Development Facilitator.

The project has gathered 10 patient stories.

It was decided that each attendee would read aloud a randomly chosen patient story. Six stories were read aloud during which time other members of the session wrote down key events, comments and feelings expressed.

The members then came together to discuss notes and discussed how best to capture the information. It was decided to break down the patient stories into a general patient experience journey of:

Patient experience journey	Key events and comments/ feelings expressed
1. Diagnosis/ First contact- A&E GP Ward Midwife	Not listening, Lack of dignity, Fearful, Honesty Just a Number, Delays in bed Good communication (important) A&E environment undignified
2. Investigations	Environment, Grateful, Clear discussion around disposal options, Honesty (important), Great staff Good communication (important), Safe, Anguish of waiting. options (be given), Kind, Supportive, Good care, Anxious, Hearing patients, Alone
3. Treatment	Unable to have family, Depending on people in the know, Kind, Supportive, Good care (ward), Distressing, Options (be given), Unimportant (Disposal), Understanding Paperwork, Time to grieve, Left for hours, Safe, Alone, Lateness of commencement of treatment
4. Discharge	Not given time to think post-op Importance of hospital Chaplain Emotional attachment to staff Ideas to move forward
5. After support/ follow-up	Unable to have a service Need for regular scans following subsequent pregnancies Lack of support after event Need for support information/signposting

From these thoughts comments and feelings three main themes emerged about what was important to women about their care. These are as below:

Safe Space – providing a space which is private, supportive staff

Active Listening – individualised treatment

Honest and Open Relationship – sensitive but factual and truthful, information giving

Plan

Project Leader to

- Organise drop-in sessions for ward staff
- Compile second Newsletter for staff and patients
- Organise a stakeholder meeting to feedback results and decide on the best way to communicate patient stories

Appendix 6

 <p>Patient Story Quote</p>  <p>Bardd Isychyd Prifysgol Ipswell Dale University Health Board</p>  <p>Burdett Trust for Nursing</p> <hr/> <p>"There was no post-surgery support. I understand that babies lost later in pregnancy are acknowledged by hospital staff and a memory box is provided along with leaflets and contact details of support"</p>	 <p>Patient Story Quote</p>  <p>Bardd Isychyd Prifysgol Ipswell Dale University Health Board</p>  <p>Burdett Trust for Nursing</p> <hr/> <p>"Staff managed to preserve the little dignity I had left, I felt safe"</p>
 <p>Patient Story Quote</p>  <p>Bardd Isychyd Prifysgol Ipswell Dale University Health Board</p>  <p>Burdett Trust for Nursing</p> <hr/> <p>"Staff were all so lovely and empathetic, I couldn't have asked for better"</p>	 <p>Patient Story Quote</p>  <p>Bardd Isychyd Prifysgol Ipswell Dale University Health Board</p>  <p>Burdett Trust for Nursing</p> <hr/> <p>"For hours after this I cried"</p>
 <p>Patient Story Quote</p>  <p>Bardd Isychyd Prifysgol Ipswell Dale University Health Board</p>  <p>Burdett Trust for Nursing</p> <hr/> <p>"I would love to have had details about the Miscarriage Association or support groups in the area"</p>	 <p>Patient Story Quote</p>  <p>Bardd Isychyd Prifysgol Ipswell Dale University Health Board</p>  <p>Burdett Trust for Nursing</p> <hr/> <p>"I went home a wreck I wanted my baby back"</p>
 <p>Patient Story Quote</p>  <p>Bardd Isychyd Prifysgol Ipswell Dale University Health Board</p>  <p>Burdett Trust for Nursing</p> <hr/> <p>"I was taken almost straight away to Picton this time and given an examination in the storage cupboard"</p>	 <p>Patient Story Quote</p>  <p>Bardd Isychyd Prifysgol Ipswell Dale University Health Board</p>  <p>Burdett Trust for Nursing</p> <hr/> <p>"Support and hugs I received while I cried"</p>

 <p>  Patient Story Quote   <small>Burdett Institute of Pregnancy Hypertensive Disorders University Health Board</small> </p> <p>"I took a long time to grieve for the babies I lost and I truly think I would have coped better if I had been able to have a ceremony"</p>	 <p>  Patient Story Quote   <small>Burdett Institute of Pregnancy Hypertensive Disorders University Health Board</small> </p> <p>"The staff that helped that day were great"</p>
 <p>  Patient Story Quote   <small>Burdett Institute of Pregnancy Hypertensive Disorders University Health Board</small> </p> <p>"I really think that at least an information pack should be provided for every single case, without question"</p>	 <p>  Patient Story Quote   <small>Burdett Institute of Pregnancy Hypertensive Disorders University Health Board</small> </p> <p>"After the scan I was sent to the 'quiet room' although I wouldn't class it as a room with respect..."</p>
 <p>  Patient Story Quote   <small>Burdett Institute of Pregnancy Hypertensive Disorders University Health Board</small> </p> <p>"It was a horrible, emotional thing to go through but with the amount of care and support it was an easy experience"</p>	 <p>  Patient Story Quote   <small>Burdett Institute of Pregnancy Hypertensive Disorders University Health Board</small> </p> <p>"I felt angry that the options had not been explained or offered to me"</p>
 <p>  Patient Story Quote   <small>Burdett Institute of Pregnancy Hypertensive Disorders University Health Board</small> </p> <p>"No information is given to someone who has just suffered a miscarriage i.e. leaflets, support networks, help. These women are faced to deal with it ALONE!"</p>	 <p>  Patient Story Quote   <small>Burdett Institute of Pregnancy Hypertensive Disorders University Health Board</small> </p> <p>"A follow up which I never received on both occasions should be offered along with staff to answer any questions"</p>