Women's experience of participating in a storytelling intervention about abnormal uterine bleeding for medical student education

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Abstract

Introduction: Storytelling of lived experience could be an effective educational intervention to enhance empathic communication during medical training. The aim of this study is to describe women's experiences of participating in a storytelling intervention for medical students, consisting of live online and recorded stories about their lived experience of abnormal uterine bleeding.

Methods: Semi-structured interviews were conducted with women who had lived experience of abnormal uterine bleeding and who participated in a storytelling intervention for medical students. Interviews were recorded and transcribed verbatim. A reflexive thematic analysis approach was used for analysing the data.

Results: Eight women participated in interviews, five online, two by telephone and one responding to interview questions by email. The analysis produced five themes: (1) empowered by opportunity to provide guidance to students, (2) empowered by advocating for women, (3) therapeutic to share and hear lived experiences, (4) preference for a pragmatic online format and (5) safe and comfortable setting for sharing experiences.

Conclusion: Women had a meaningful and therapeutic experience of participating in the storytelling intervention. Storytelling interventions for health professional education may work well for people with lived experience when a practical or flexible online format is offered, which contributes to a safe and comfortable environment.

Keywords: patient storytelling; medical education; women's experiences; abnormal uterine bleeding; patient experience

Introduction

Understanding the lived experiences of patients can help healthcare practitioners to deliver compassionate patient-centred care (Boissy et al., 2016; Milota et al., 2019).

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Interventions that effectively enhance understanding of lived experiences include listening to patient stories or narratives, reflections and experiential simulations (Bas-Sarmiento et al., 2020; Kumagai, 2008; Winter et al., 2022). In medical training, patient stories are increasingly being used to impart patient perspectives and experiences (Kiosses et al., 2016; McNichol, 2012; Rowland et al., 2019; Towle & Godolphin, 2013). Involving real patients and their illness experiences is considered valuable, genuine and appropriate for empathy training (Jha et al., 2009a; Kumagai, 2008). While involving patients in an educational process is valuable, it can also be challenging due to feasibility issues (Dijk et al., 2020; Lauckner et al., 2012). Exploring the experiences of patients participating in a medical education intervention could identify the circumstances that are likely to create feasible and sustainable education interventions (Dijk et al., 2020). To date, there are limited studies exploring experiences of patients and the required setting to facilitate participation in medical teaching interventions (Dijk et al., 2020; Watts et al., 2015).

Since women have reported undermining experiences from healthcare practitioners when accessing treatment for abnormal uterine bleeding (da Silva Filho et al., 2021; Henry, Ekeroma, & Filoche, 2020; Henry, Jefferies, et al., 2020), we were interested in exploring if women's storytelling during medical training would be an effective educational intervention to enhance empathic communication. Therefore, we conducted a pilot intervention study to investigate the impact of a storytelling intervention in a women's health setting on empathy of medical students (Kanagasabai et al., 2023). To provide insights into women's experiences participating in the storytelling intervention and factors facilitating their participation, we undertook a qualitative study after the educational intervention was completed. The intervention was a classroom-based session for students about lived experience of abnormal uterine bleeding, with women presenting either live online or video-recorded stories. Our aim was to describe women's experiences of participating in this storytelling intervention.

Methods

For the pilot intervention study, women were recruited from the gynaecology clinic at Wellington Hospital in New Zealand. For inclusion, women were over 18 years of age and had abnormal uterine bleeding. Eight women participated in the pilot intervention study and shared their lived experience of abnormal uterine bleeding (February–April 2022). Four women shared their stories live online, and four women shared their stories in a recorded audio-visual format. The recruitment, intervention methods and findings regarding students' post-intervention empathy scores have been reported in detail in Kanagasabai et al. (2023). Ethical approval for this qualitative study was obtained as part of the pilot intervention study from the University of Otago Human Ethics Committee (Health) H21/007. Sharing difficult lived experience can be distressing for women. We offered the hospital support services' contact information to women and an opportunity to talk to a gynaecologist if required. We have used the COnsolidated criteria for

REporting Qualitative research (COREQ) checklist for reporting this qualitative study (Tong et al., 2007).

After participation in the storytelling session, all women were invited by researcher PK to participate in an interview regarding their experience of storytelling. Researcher PK, PhD, is a trained women's health physiotherapist and works in a research-only position. Her research interests include improving access to care for people with gynaecological conditions. She was involved in the recruitment of women for the pilot intervention study, and she introduced herself and explained the background, rationale and purpose of the study to the participants. Women were provided with the study information sheet and the contact details of researchers for more information. PK was also involved in conducting the storytelling pilot intervention and collection of recorded stories, so she had a relationship with the women prior to the interviews, which was helpful for building rapport. Informed consent was obtained from women as part of the pilot intervention study (Kanagasabai et al., 2023).

Qualitative semi-structed interviews were conducted to explore women's experiences and needs, including barriers and facilitators for participating in the storytelling study (Adeoye-Olatunde & Olenik, 2021). Women were offered an interview online via Zoom™ or by telephone: five participated in interviews online, two by telephone, and one responded to interview questions by email. Seven participants were in their home, and one was in her office environment during the interviews. The duration of interviews ranged from 4 to 14 minutes. Interview questions were provided to the participants before the interview session (Table 1). Interviews were recorded and transcribed using the Otter AI app™. The transcriptions were then manually checked for correctness.

Table 1

Interview Guide for Women

Exploring experiences
Q1. How did you feel about sharing your experience with medical students?
Exploring barriers and facilitators
Q2. How difficulty or easy it was for you to participate in the study (barriers)?
Q3. What can we do to support you to participate in the program (facilitators)?
Q4. What made you choose this type of format (online Zoom / recorded videos) for sharing your experience?
Q5. Would you like to do storytelling again or on a regular basis?
Q6. Would you agree for your recorded stories to be stored and used on a regular basis as part of teaching program for medical students? (for recorded storytelling participants only)

The data was analysed by PK using reflexive thematic analysis (Braun & Clarke, 2019). Another independent researcher (CH) read the transcripts and analysed the data. In this process, the transcripts were coded, with key phrases or sentences that related to

women's experiences and barriers or facilitators for participation in storytelling identified. The codes were then grouped into categories based on similarities and differences, and themes were derived. The codes, categories and themes derived by both researchers were compared and then discussed with a third researcher (SF) to ensure accuracy and identify any additional themes. The developed themes and relevant quotes were sent to the participants for the member-checking process, with the participants invited to comment or add additional information on the study findings (Creswell & Miller, 2000). In the member-checking process, we had positive comments from four participants. No participants provided additional information.

Results

Eight women participated in the storytelling study and interviews, with ages ranging from 23–61 years. The women involved had experienced abnormal uterine bleeding for 2 to 10 years. Women identified their ethnicity as New Zealand European (3), Māori (1), New Zealand European and Māori (1), New Zealand European, Māori and Samoan (1), Sri Lankan (1) and Filipino (1). The themes identified from the analysis of interview data are described below. We have used participant numbers only to maintain participants' anonymity.

Empowered by opportunity to provide guidance to students

Participants expressed that they were happy to be involved in teaching and said it was a meaningful and enjoyable experience. They participated in storytelling as it provided them with the opportunity to provide insights to the students, to help them and to improve the medical system as a whole. Participants felt it is important and necessary to help students become more empathetic and understanding of patient experiences from multiple perspectives. They also hoped that because the listeners are medical students, they will take women's experiences seriously and understand that it is quite a common theme amongst a lot of women. They considered stories powerful and suggested they can help medical students learn. One participant who shared her story live with students stated:

> *I'm perfectly happy to share my experiences with medical students, because I'm hoping that in a very small way, it might help them with their learning. And that's, that's important. We all benefit from that. ... I didn't share my story very much with anybody a lot, you know, but having, you know, in the context of sharing it to medical professionals and people who are interested to know to help them with their learning, that's different in my mind. ... It's helping them to help other people like me going forward.* (Live storytelling, participant 3)

Empowered by advocating for women

Participants believed that storytelling provided them with the opportunity to improve healthcare experiences of other women seeking treatment. Those who had had poor

experiences with medical care for abnormal uterine bleeding believed that they could potentially prevent other women going through a similar negative experience. Participants used phrases such as "I cry and cry", "it was painful; it hurt my life", "for someone that is feeling depressed" to indicate their experience of abnormal uterine bleeding and to describe that it is necessary to advocate for women. They expressed that they saw people share stories on TV news and social media and that it was an encouragement to share their lived experience and help other women. One participant said:

> *I feel like it's a very necessary thing. I'm more than comfortable to do it. If it means that I'm potentially, I'll be, saving another woman from kind of going through my experience.* (Recorded storytelling, participant 3)

Therapeutic to share and hear lived experiences

Participants expressed that they had a healing experience, as the storytelling session provided an opportunity to share their stories. They felt it was therapeutic for them, as they rarely talked to anyone about how it felt to live with abnormal bleeding. Women who participated in the live storytelling intervention indicated that they had the opportunity to hear the stories of other women, which helped them to connect with other women who are going through the same situation and provided peer support. One participant expressed:

> *I feel good actually … because I cannot talk about it to my husband. You know, because this is a women thing. … It's not about bragging what you have, but just to get it out from your chest … and after that, that's it, all good.* (Recorded storytelling, participant 2)

Preference for a pragmatic online format

Participants appreciated the flexible timing option the digital storytelling format had provided. Those with work commitments felt that a live online or recorded storytelling would not intrude into work. One woman who participated in the live intervention indicated that more notice of session timing would be helpful. Participants acknowledged that recorded stories have the advantage of reaching many people and is easier, as the recording can be done at a suitable time. While participants thought that an in-person session would impact students more, as students can perceive the body language, they also acknowledged that a digital format is more practical in terms of work commitments and more suitable for their health situation. One participant stated:

> *I like the face-to-face session, however when I am travelling for work, this may not be as easy to fit in, so the digital storytelling would suit me more I think probably long term. ... But yeah, I just don't want to commit to something that I might not be able [to commit to]".* (Live storytelling, participant 1)

Safe and comfortable setting for sharing experience

Participants considered a safe storytelling environment of their preference important while sharing stories. For sharing stories live online, participants chose a private home or office environment. For the live intervention, being able to join in from the workplace environment was a consideration for women.

All participants who chose live intervention expressed that they were comfortable sharing stories with a small group of students. A recorded format was considered preferrable by those who were not comfortable facing a group of students and those who preferred a non-threatening setting and experience of sharing stories. One participant expressed:

> *It was easier for me to be able to just do it at home. And also, I guess, talking about the experience to be able to be as comfortable as possible. … I'd be able to kind of, like, I guess, tell the stories quickly and as best as possible. Whereas maybe I can imagine myself taking a while to get to the point and overthinking everything if I took it too seriously and got all dressed up and went out and met you and all of that stuff. And then it was just easier to talk to in a more casual setting for me.* (Recorded storytelling, participant 3)

None of the participants mentioned payment as an enabler for sharing lived experience. One participant identified a travel fund, as a bonus, if travelling was part of the teaching session. All women who participated in the recorded storytelling intervention consented for their video to be stored and used on a regular basis for medical teaching. Three women who participated in the live intervention were keen to share their lived experience with students again and on a regular basis with enough notice. None of the women in our study reported distress and the need to utilise the support services offered.

Discussion

Our qualitative study explored women's experiences of and preferences when participating in a storytelling intervention for medical students. Participants reported that sharing their lived experience with medical students was a meaningful, empowering and therapeutic experience. They highlighted the importance of a pragmatic time-flexible online format and a safe and comfortable environment to share stories.

Participants in both the live and recorded intervention felt that stories are powerful and that they will help guide students to understand women's experiences of living with abnormal bleeding issues and lead to compassionate care. Feelings of altruism, empowerment and wanting to educate or influence future doctors have been reported by patients as key motivating factors for engaging in medical teaching programs (Bokken et al., 2008; Dijk et al., 2020; Mol et al., 2011; Watts et al., 2015). The experience of abnormal bleeding had a huge impact on the women sharing their stories and motivated them to advocate for other women going through the same experience. The storytellers hoped to improve the experience of others in the healthcare system.

Women reported positive experiences from participating in the study, and none of them reported embarrassment from sharing their experience of abnormal uterine bleeding. Menstrual issues are rarely discussed in the family and community due to taboo and social stigma (Henry, Jefferies, et al., 2021). Participants had therapeutic benefits from sharing their lived experience, as the intervention provided the opportunity to share their feelings as well as enabled them to connect with other women experiencing similar issues, which gave them peer support. Women in the live storytelling intervention liked speaking as a panel and felt the support and acknowledgement of peers in a similar situation. Women have reported positive feelings of empowerment and acceptance when engaging with other women in the community with similar health issues (Sanigorska et al., 2022).

Participants considered the online storytelling intervention format suitable, as it provided them with flexibility timewise and could align with work commitments. In particular, they considered a safe and comfortable environment for sharing their experience important, and our intervention provided women with the opportunity to share their experience in their casual home setting. The location of teaching and support provided is considered important for the wellbeing of patients as they are retelling their painful experiences (Jha et al., 2009b). Being able to participate in their own environment, such as a home setting, is reported to be helpful for patients engaging in medical teaching (Jha et al., 2009b).

The views of the women who participated in the storytelling intervention may differ from other women who declined to participate. Women who did not participate in the intervention study stated reasons such as having stress or pain, other family and work commitments, not willing to share personal issues and not comfortable talking to a group. Involving real patients for medical teaching has been reported to be challenging for reasons such as patients' unpredictable availability and physical condition (Jha et al., 2009a). Difficulty sharing sensitive information has also been reported as a challenge in previous studies (Dijk et al., 2020). A limitation of the study is that we did not ask women about the recruitment strategy. We recruited women from the gynaecology clinic at Women's Health Service, Wellington Hospital. We believe inviting women through other means, such as social media, could have been more feasible. We have also not reported on other aspects of arranging the learning intervention, such as academic and administrative time, technical requirements and costs.

Conclusion

The women in our study had a meaningful and therapeutic experience of participating in a live and recorded storytelling intervention for medical students. This study highlights that women could be a part of medical teaching when provided with a practical online format of sharing their experience in a safe and comfortable environment. Patient involvement in health professionals' education is highly valuable for learning. This

qualitative study showed that a storytelling intervention is feasible for women. We recommend future studies explore women's active engagement in design and evaluation of women's health curriculum.

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Conflicts of interest and funding

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