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‘Reconstructing Ourselves’ – An arts and research project improving patient experience

ABSTRACT

‘Reconstructing Ourselves’ was an eighteen-month arts project that brought together a visual artist, a storyteller and a qualitative researcher. The team worked with women undergoing complex breast reconstruction and facilitated them to tell their stories through video, textiles and photography as well as directly to their doctors through narrative recordings played during their consultations. This article focuses on the narrative recordings which were the subject of the research question: Can pre-recording what patients want to say before they go into the consultation room improve the patient experience of the consultation? The article describes the methodology and key thematic findings from twenty women who played their recorded narratives directly to their doctors. The response and feedback given by all participants in this study overwhelmingly confirmed that pre-recording what patients want to say, and playing it as part of the consultation, improved the patient experience of the consultation.

KEYWORDS

consultations
doctor–patient
co-production
audio-recordings
narrative
patient story

INTRODUCTION

To improve the patient experience, the Abertawe Bro Morgannwg University (ABMU) Health Board is developing an extensive programme of arts-led activity. In 2012 Prue Thimbleby was appointed as arts coordinator for the Health Board. One of the first projects Thimbleby, who is also a storyteller, initiated was a patient story project where facilitators guide patients in recording their health service experiences including issues and concerns. These voice recordings are edited to create a two-minute story. The recording is combined with patient-selected imagery to create a short digital video. These videos (called patient stories) have been shown at the beginning of many meetings, including those of the Board of Directors, Quality and Safety Board and at the ward level. The aim of showing the stories is to keep the patients' voices central to decision making as administrators and clinicians work to continually improve patient services.

In 2013 Hamish Laing, who was Director of the Welsh Centre for Burns and Plastic Surgery, asked Thimbleby to seek funding to employ Rhian Solomon as Artist in Residence in Plastic Surgery. It was during the project planning that the idea of women recording what they wanted to say to the doctors prior to the consultation was raised by Thimbleby whose work with the patients inspired this creative thinking about the use of story and patients' voices. While there is considerable documentation of the idea of patients recording what doctors say in consultations (Elwyn et al. 2015) we could find no evidence of any research being done with patients taking their own recordings into consultations. A research question was formed and a qualitative researcher, Sarah Wright, was added to the residency team. Thus, in the 'Reconstructing Ourselves' project (<http://www.artsinhealth.wales/reconstructing-ourselves.html>) the patients' stories were developed beyond the short digital stories for use in meetings as they were trialled in new contexts and told through new mediums including textile art and photography.

'Reconstructing Ourselves' was an Arts Council Wales funded artist residency exploring the stories, lives and experiences of patients undergoing complex breast reconstruction at Morriston Hospital in Swansea from April 2014 to October 2015. The clinicians wanted to explore new ways to understand their patients' experiences. A storyteller, a visual artist and a qualitative researcher worked with clinicians and patients – listening, talking, interpreting and recreating the detailed dialogues and narratives of the people that they met. Some of the outcomes from that wider project are described below before describing the qualitative research study focused on voice recordings that were made prior to and used in doctor-patient consultations.

Many patients undergoing breast reconstruction have questions about the procedure and their options. Solomon was the visual artist for the project; her practice is concerned with drawing parallels between skin and cloth, the body and dress. She led a series of art workshops with the patients, facilitating creative works in response to their experiences such as nipple reconstruction. Solomon brought together plastic surgeons, patients and Juliana Sissons, a couture pattern cutter, for a one-day workshop to compare the differences and similarities between the two practices of plastic surgery and pattern cutting. How do pattern cutters cut cloth and shape garments compared to plastic surgeons cutting and reshaping flesh? What can the two professions learn from each other? Following the workshop, using what was learnt from the surgeons and the patients, a textile model was created by Solomon and



Figure 1: Demonstrating Breast Reconstruction, 2015. Textile model. 80×30×30cm. Photograph copyright Rhian Solomon and Juliana Sissons.

Sissons which can be manipulated to demonstrate two different types of breast reconstruction. The model is now being used in the complex breast reconstruction clinic to demonstrate different options for surgery (Figure 1).

Following many conversations with the patients and seeking new ways for them to tell their stories, Solomon worked with photographers in the hospital's Medical Illustration Department to take photographs of seven of the women wearing different articles from their wardrobes. The different outfits documented their patient journeys, starting when they were diagnosed with breast cancer, through the experience of mastectomies and further treatment before undergoing complex breast reconstruction (Figure 2). Each series of photographs was accompanied by an artist-created book telling the patient's story.

In another activity, to enable the patient's voice to be heard widely, Thimbleby worked with a different group of the women to create ten digital patient stories (short videos) telling of their experiences from full body scans to false expectations, from relationship challenges to loss of libido. These short videos have been shown in conferences, hospital corridors and many gatherings of women.



Figure 2: The Patient's Journey through Fashion, 2015. Photograph copyright Rhian Solomon.

Wright led the qualitative research to address the question: Can pre-recording what patients want to say before they go into the consultation room improve the patient experience of the consultation? She worked with women in the breast reconstruction outpatient clinics of two consultant plastic surgeons: Amar Ghattaura and Mark Cooper. She facilitated the women to record what they wanted to say to their doctor and to play it in the consultation. She then collected post-consultation feedback from the patients and the doctors as well as her own observations.

The three members of the residency team worked in close collaboration over a period of eighteen months. The project culminated in a symposium and exhibition that showed the work created by the visual artist, ten digital patient stories and the research results that were delivered through creative mediums such as acting and a film animation.

RESEARCH RATIONALE

The doctor-patient consultation is an encounter between two people, and represents the bedrock of medicine. It underpins and provides the platform for a relationship of care built on mutual trust, empathy and communication. It is a space for both the doctor and the patient to impart knowledge through spoken words using culturally accepted language as well as very often technically heavy jargon. It is also an opportunity to interpret information and simultaneously arrive at critical decisions that shape an individual's life, both physically and emotionally.

The structure imposed upon the practice of consultation with patients is based upon rich professional experiences developed by doctors and healthcare professionals over many years of practicing in specialized areas of medicine (Mauksch 2017). However, the necessity to deploy a framework approach to managing the complex nature of consultation with a patient is also borne out of the need to manage the increasing demand, which often outweighs capacity of resource, in managing growing cohorts of patients in all areas of health. It is well-evidenced that traditional practices of consultation typically follow pre-determined algorithms formed

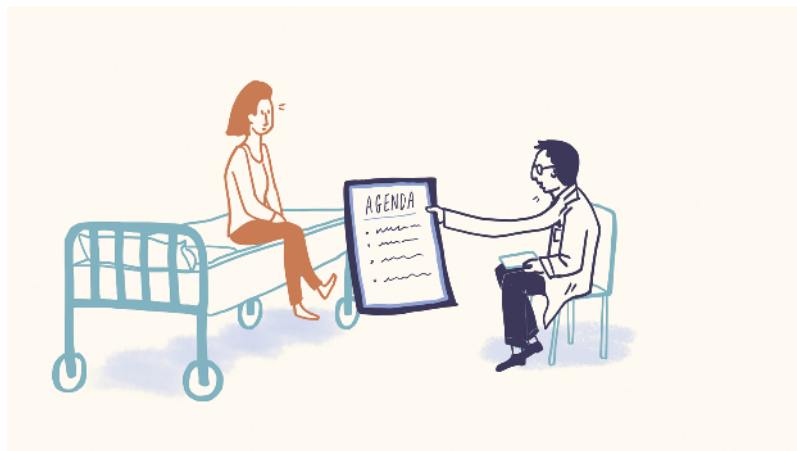


Figure 3: The Doctor setting the Agenda, Digital drawing. Photograph copyright Laura Sorvala and Sarah Wright.

by healthcare professionals with frequent interruptions of the patient's narrative by the professional. Research shows that, despite an intention to listen to the patients' stories, a doctor will interrupt the patient on average within eighteen seconds of the patient starting to talk (Beckman and Frankel 1984; Marvel et al. 1999). It could be argued that today's stretched healthcare system inadvertently enforces an impersonal logic into the way that consultations are carried out. Yet it is not always time efficient. Graham Easton (Programme Director, Imperial GP Specialty Training, Department of Public Health and Primary Care) says, 'When the patient's narratives are interrupted, the consultation becomes less patient centred, and patients tend to start telling their narratives all over again, taking even more time.' (Easton 2017: 25).

Sociological health services research and other popular discourses in health and well-being suggest that these frameworks are perpetuated by traditional practices that are upheld by the dominant powers of the healthcare system. And, as such, there exists an uneven distribution of power within the clinical encounter of the consultation. Fischer and Ereaud say that the practice of consulting patients needs to move away from 'the fragmented nature of conversations [...] in which the patient is the only person to join up the narrative' (2012: 5).

'Reconstructing Ourselves' provided a real opportunity to pilot a new co-produced method of consultation aimed at enhancing the patient experience of women undergoing complex breast reconstruction. The study aimed to improve understandings among clinicians of patients' narratives and encourage patients to be empowered to co-produce the consultation with their doctor, thus directly responding to the need to reconsider traditional practices of consultation in secondary care and the need to strengthen the patient-doctor alliance.

RESEARCH METHODS

Qualitative research employs descriptive and inductive techniques to understand social phenomena. This study adopted a mix of qualitative methods to evaluate women's experiences of using pre-recorded narratives as part of consultations with breast reconstruction plastic surgeons in outpatient clinics. The following describes the study's participants and how data was collected.

PARTICIPANTS

The participants were women undergoing complex breast reconstruction who fell into one of the following three groups:

- Immediate – Women undergoing an immediate breast reconstruction at the same time as a mastectomy.
- Delayed – Women undergoing delayed breast reconstruction after a mastectomy.
- Genetic – Women undergoing breast reconstruction following an at-risk diagnosis for developing breast cancer.

While the majority of women undergoing complex breast reconstruction fall into the first two groups (immediate and delayed), the study included participants from each of the three groups. Wright worked closely with the consultants and their administrative teams to identify a range of women from the

three different groups above and those having different types of operations and at different stages of treatment including post operative. The women were given information about the project and the opportunity to be included in the study.

ETHNOGRAPHIC DATA COLLECTION

As part of the study, Wright observed a number of clinic consultations led by the two plastic surgeons over a time period of several months including six full morning consultations. Her initial observations were made in consultations where the women had not created an audio recording; this enabled the researcher to gain an insight into how 'typical' consultations were conducted in this setting. The ethnographic observation was not limited to observing the encounter between patient and doctor, but also involved observations of routine practices and the social organization of the clinic in terms of the people involved in treating and caring for patients. Wright's observations are discussed in the Research Results section.

AUDIO RECORDINGS AND FEEDBACK COLLECTION

Based on the insights gained into the way that outpatient clinics and the individual patient appointments are conducted, Wright worked with the staff to choose the most appropriate time, place and space for the recordings to be made. The Medical Illustration Department made a nearby space furnished with armchairs and a coffee table available for the recordings to be created.

Wright worked with twenty women, only one of whom she had met during the period of observation, to make audio recordings to playback in their consultations. Some patients were identified in advance by the consultants. These patients were contacted by the consultant's administration team and given verbal information about the project over the phone. If they wanted to take part, they were then asked to attend their clinic appointment a little earlier than the specified time to make the recording. Other women were identified by the clinical team the day before the clinic. Wright met all the women identified and gave them information sheets and consent forms and answered any questions. All the women asked were willing to take part.

The patients were then shown to the comfortable sitting room in the Medical Illustration Department and the researcher put the participants at ease as much as possible. The researcher gave brief instructions about how the recording would be done. For the first two clinics a voice recorder was used but finding the right recording to play in the consultation was more difficult and a smart phone was found to be a more effective tool. The study participants were encouraged to record the key issues, concerns and questions that they wished to discuss with the consultant. The researcher used a consistent approach to provide information and support the patients in articulating what they wanted to say and recorded this on a smart phone app. The researcher then observed the consultation when the audio recording was played.

Women who participated in the creation of audio-recordings were invited to complete a brief open-ended post-consultation feedback form designed to capture descriptive information about the experience of consultations using audio-recordings. The form simply stated:

Are you ready for your consultation today?

Prepare for your consultation today



This infographic illustrates the process of using pre-recorded audio files in clinical consultations. It forms part of the research findings from the Structuring Greetings Arts and Health project. Special thanks to all the patients and staff from the Welsh Centre for Burns and Plastic Surgery Outpatient Department at Morriston Hospital who were involved in this research.

Created by Sarah Wright (2016)



Figure 4: Infographic describing the research methodology. Photograph copyright Laura Sorvala and Sarah Wright.

We would like to receive your feedback on your experience of today's consultation with the doctor. Please feel free to write down any thoughts, comments and feedback you wish to provide about the way in which you experienced the consultation. Completed forms can be placed in the box at the reception desk or handed to the researcher. We are very grateful for your time and support. Thank you.

The original research design had included post-consultation qualitative interviews to provide more in-depth feedback about both the consultation and the use of pre-recorded audio recordings. As only one participant consented with others citing time constraints for their decision, the interviews were not conducted. However, the researcher did gather the written feedback from the open-ended form as well as some informal verbal feedback from several participants post-consultation.

ETHICAL APPROVAL

The Research Ethics Committee for Swansea University granted full ethical approval in addition to Research Governance permissions from the Morriston Hospital. The study was also granted a favourable opinion from the Joint Scientific Research Committee (JSRC).

RESEARCH RESULTS

Ethnographic observations before using audio recordings

Wright observed that the sequence of consultations involved warm greetings from the outpatient reception team; health care assistants personally escorted women to consultation rooms and prepared the patients for the consultation by providing gowns. The consultation rooms were sparse spaces; the only items of furniture were a hospital couch, a chair and a sink. There was a single picture on the wall and a mirror. The patient then waited in the room whilst the doctor reviewed the notes in a separate area.

Once the doctor arrived, typically chaperoned by at least one more person, they initiated the conversation by asking the patient for their medical history and the purpose of attending outpatient clinic. There were two core elements to the consultation that were led by the doctor: (1) the physical examination and (2) a well-articulated outline of the options for complex breast reconstruction, which was often supported by artistic illustrations drawn by the doctor directly into the patient health record for the woman to see. The doctor also sometimes drew directly on to the woman's body to show 'what bit would go where'. They were also supported by referencing a small book of photographic images illustrating the outcomes of reconstruction for other patients (all anonymous).

Themes of conversation during consultations included discussions about options for surgery, risks, post-surgical treatment and matching the symmetry and volume of breasts. Wright observed that, whilst the manner in which the doctors talked to their patients was unambiguous and empathetic, they very often monopolized the conversation. Additionally, doctors often used terminology that could be confusing or off-putting to patients such as 'dog ears' which referred to the excess flesh around scars following surgical procedures and 'donor sites' used to refer to parts of the body that flesh and fat can be taken from to use for the reconstruction.

It was clear that the abundance of information and challenging decision-making associated with choosing breast reconstruction required time for consideration. For women facing an imminent mastectomy the decision had to be made far more quickly than for those women who had attended as delayed breast reconstruction patients.

Wright observed that patients could and did ask questions, such as 'How much time will I have to take off from work?', 'What pain is to be expected?', and 'What sort of bra should I wear afterwards?' But for some patients she observed body language that suggested vulnerability and shyness that overshadowed their voices. In a qualitative study where women were interviewed regarding their concerns prior to consultations and then the consultations were recorded Barry et al. concluded that:

Patients have many needs and when these are not voiced they can not be addressed. Some of the poor outcomes in the case studies were related to unvoiced agenda items. This suggests that when patients and their needs are more fully articulated in the consultation better health care may be effected. Steps should be taken in both daily clinical practice and research to encourage the voicing of patients' agendas.

(2000: 1)

In this period of ethnographic observation, before the audio recording was introduced, Wright observed that clinicians conducting consultations showed care and compassion with their patients, but the doctors dominated the conversation and missed opportunities to engage with patients whose voices were easily overshadowed by the doctors.

Observations of the impact for the women making the audio recordings

All participants approached the creation of their audio-recordings tentatively, rather than assertively. For some, the articulation of their concerns, issues and questions was more challenging than for others by virtue of the sensitivity and enormity of the reconstructive process and the experience of cancer.

Wright observed that, in contrast to the questions asked in the traditional consultation, patients used the recording to offer more specific concerns and thoughts for the doctor to hear including those they described as 'trivial'. The recording was less intimidating than raising them face-to-face. For example they said: 'I want to wear normal clothes, but my breast looks like a vegetable', 'I should have had a double mastectomy' and 'This is impacting on my marriage; I don't like to let him see me like this'. Women wanted to tell their doctors that they were finding it difficult to live with their reconstructed breast but at the same time they were concerned that the doctor could interpret that negatively. Some women were concerned about offending the doctors with such issues. The recording seemed to offer them an opportunity to express their thoughts more freely. Indeed, some women appeared liberated by the ability to use the audio recording to ask for what they really wanted. For example: 'I don't like asking but can I reduce the other side a bit? And lift it a bit too?'

The recording offered the women a chance to express thoughts they otherwise internalized such as their motivation for even having the surgery. While enhanced appearance was a goal for some patients, it was neither the only type of personal goal referred to, nor was it something that everyone wanted

to achieve. One woman said, 'If I didn't have a husband I wouldn't bother doing this' indicating that the motivation and desire for breast reconstruction is not always driven by the patient but others too.

Many women remarked about their desires to be 'normal' and there was a notable repetition in the recordings to suggest that simultaneously they are also 'renegotiating the notion of what's normal' for themselves. The recordings allowed women to share things with their doctor about their experience of renegotiating their appearance, sense of normal and femininity.

Women also wanted to use the audio recordings to express gratitude or grievance at the outcome of the appearance of the breast. Some women expressed that they would have preferred to know more about the risks associated with unexpected outcomes related to the appearance of their reconstruction. For one particular woman, understanding as much about the potentially less desirable outcomes of complex breast reconstruction may have altered her decision-making around choosing this elective surgery.

The method of pre-recording narratives empowered the women to think about their relationship with their doctor and to raise concerns in a non-confrontational way. They expressed that the dynamic between the doctor and themselves changed as a result of being listened to and 'owning' a part of the consultation and some women made suggestions about how consultations and the journey of complex breast reconstruction could be improved.

Observations of the impact of the audio recordings on the consultation

Wright observed new practices developing in response to the playback of the audio recordings. The doctors formally noted key points from what the women talked about in the recordings directly into the patient medical record. They then proceeded to address each issue in turn, adeptly altering their traditional algorithmic approach into an interaction that addressed individual needs, questions and concerns and fears.

In debriefing at the end of the project, the doctors observed that, rather than taking longer as they had feared, listening to the recordings was actually a very efficient use of time allowing them to quickly hear and address the patient's questions and concerns. One consultant has since asked for his patient admission letters to be changed to suggest that patients bring in a recording to play. This has not been followed through yet due to changes in staff. We hope that a follow on project would build more sustainable change in practice.

CONCLUSIONS

The idea to use pre-recordings in doctor-patient consultations came from artists working with clinicians, illustrating how an artist can bring new perspectives to traditional practices. Using audio recordings that detail the patient agenda disrupts the traditional algorithmic approach to consultation in favour of a co-produced approach to consultation. As observed in this small study, both patients and doctors note improved satisfaction in the consultation experience through this intervention.

The women enjoyed the opportunity to focus their minds in readiness for consultation. So often the women reported that they would forget what they wanted to ask – but the audio recording allowed them the chance to go into the consultation knowing they had already set out what they needed from the consultation. They appreciated the uninterrupted time allocated to listening to

what they wanted to say and then they could focus on listening to the consultant's response. The doctors discovered the recordings allow for more efficient use of time while also connecting more effectively with their patients.

The response and feedback given by all participants in this study overwhelmingly confirmed that pre-recording what patients want to say before they go into the consultation room and playing it as part of the consultation improved the patient experience of the consultation and enabled the doctors to efficiently address the patients' concerns. It is recommended that additional projects be conducted to further examine the efficacy of this arts-based intervention.

FURTHER RESEARCH QUESTIONS

While the sample size was small for this study, the results are encouraging and warrant additional research. There are further questions to address such as: 'How can pre-recording become a regular practice in consultations?', 'Does it need to be facilitated or can patients be empowered to bring in recordings on their smart phones?', 'Should the audio recordings be stored as part of the patients' medical records?', and 'Does this intervention deliver better long-term outcomes than the traditional model?'

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CONTRIBUTOR DETAILS

Prue Thimbleby is a midwife who has worked in participatory arts for the last twenty years. She now works as arts in health coordinator for ABM University Health Board where she leads a small arts team. The job involves everything

from making videos with patients so they can tell their stories, to setting up music performances, to facilitating an artist in residence programme and raising the funds to make it all happen.

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Sarah Wright, Ph.D. is a medical anthropologist and qualitative researcher. Her doctoral research in patient centred care in gastroenterology and other research has explored the notion of patient-centred professionalism in the contexts of community pharmacy and community nursing. More recently Sarah has been involved in research and evaluation of the delivery of mental health services and dermatology services in Wales. Her current roles include leading the implementation of Patients Know Best in Wales and acting as Vice Chair for an all Wales skin charity.

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Rhian Solomon is currently a Ph.D. student at the University of the Arts, London and Co-Director of OurOwnsKIN, a consultancy rethinking design for the body. Rhian's practice interrogates contemporary perspectives of the human body. Brokering interactions between the design and medical communities, she creates projects that conceptually blur boundaries between the interfaces of skin and cloth, the body and dress. Her collaborative network, SKINship, emphasizes the body as a meeting place between reconstructive plastic surgeons, patients and designers. Rhian's practice has been commissioned by and presented at the Welsh Centre for Burns and Plastic Surgery, Wellcome Trust, British Association of Plastic Reconstructive and Aesthetic Surgeons, NIKE Design Kitchen, Maggie's Cancer Care, Leverhulme Trust and the Arts and Humanities Research Council.

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