

The acceptability of PEGASUS: an intervention to facilitate shared decision-making with women contemplating breast reconstruction

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Good practice guidelines recommend that women who undergo mastectomy are offered reconstructive surgery. However, many who choose this option report a degree of decisional regret and dissatisfaction because their pre-surgical expectations were not met. This paper reports an acceptability study of a new intervention (PEGASUS) that aims to support shared decision-making by eliciting women's pre-surgical expectations and setting patient-centred goals. Eighteen women contemplating breast reconstruction completed the PEGASUS intervention. Semi-structured interviews were conducted with 12 women and 3 health professionals to explore their experiences of using PEGASUS. Interview transcripts were subjected to a thematic analysis, and a content analysis was conducted on 79 goals that the 18 women identified. Feedback was extremely positive – women found that completing PEGASUS alongside a discussion with a specially trained health professional helped them prepare for the surgical consultation and increased their trust in their surgeon. Staff reported that PEGASUS facilitated patient-centred discussions and informed the decisions made about potential surgery. This preliminary study suggests that this novel intervention is acceptable to patients and health professionals alike. Further work is needed to evaluate its efficacy and then its effectiveness with a larger sample of women, and its potential use with other patient groups.

Keywords: shared decision-making; breast reconstruction; PEGASUS; intervention; acceptability

Introduction

Each year, over 5000 women in England undergo reconstructive breast surgery after mastectomy (National Mastectomy & Breast Reconstruction Audit, 2011), either simultaneously (immediate reconstruction) or at a later date (delayed reconstruction). Although reconstruction aims to preserve quality of life and body image, studies (e.g. Sheehan, Sherman, Lam, & Boyages, 2007) suggest almost half (47%) of patients report some degree of regret about their decision. The National Mastectomy & Breast Reconstruction Audit (2011) reported 1/3 of immediate and 22% of delayed reconstruction patients remained disappointed with outcome at 12 months. Women's dissatisfaction often relates to pain (Harcourt & Rumsey, 2004) and scarring (Abu-Nab & Grunfeld, 2007) and has been associated with expectations of surgical outcome or process

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(Sheehan et al., 2007). However, their expectations are often unclear (Snell et al., 2010). Therefore, clarifying patients' expectations, preferences and values is key.

Active patient involvement through shared decision-making is associated with more positive patient experiences and outcomes (Dept. of Health, 2010), particularly 'preference-sensitive' decisions like those about breast reconstruction (Politi, Dizon, Frosch, Kuzemchak, & Stiggelbout, 2013). Several breast surgery decision aids (Caldon et al., 2010; Lam et al., 2013; Sivell et al., 2012) are available, but clinicians report concerns that they are not tailored to individual needs, could replace nurses' roles or induce patient anxiety (Caldon et al., 2010). Recently, attention has shifted to decision coaching to facilitate patients' preparations for shared decision-making about preference-sensitive decisions (Stacey et al., 2012).

PEGASUS (Patients' Expectations and Goals: Assisting Shared Understanding of Surgery) aims to elicit expectations of reconstruction, to aid discussion and setting of patient-centred goals. It is provided after a woman has received information about her specific surgical options. A psychologist helps the patient identify her individual goals for surgery and what she considers indicative of a successful outcome. These are summarised and the patient rates each goal (from 0 to 10) in terms of its importance. This takes around 45 min. The PEGASUS sheet is then used in the surgical consultation to set shared goals and promote concordance between the patient and surgeon (Stevenson, Cox, Britten, & Dundar, 2004). The surgeon rates the probability of achieving each patient-set goal (from 0 to 10), thus facilitating discussion about whether expectations are realistic, before final decisions about surgery are made.

This paper reports patients' and clinicians' feedback on the acceptability of PEGASUS, an important but sometimes overlooked aspect of piloting work when developing, evaluating and implementing complex interventions (see Craig et al., 2008).

Method

This study was conducted in a large NHS hospital offering breast reconstructive procedures.

Participants

Eligible women were over 18 years of age, had a diagnosis of breast cancer or ductal carcinoma in situ (a pre-invasive condition) or were considering risk-reducing mastectomy, and were contemplating immediate or delayed reconstruction.

Procedure

NHS and university ethics and R&D approvals were obtained. Eligible women were identified from clinic lists, sent the study information and invited to an appointment where the PEGASUS intervention (outlined above) took place. Patients and health professionals were invited to a semi-structured telephone interview, conducted by CG, about experiences of using PEGASUS and its future evaluation and implementation. Interviews were audio recorded and transcribed verbatim.

Analysis

Women's goals for reconstruction were subjected to a content analysis (Krippendorff, 1980). Thematic analysis of interview transcripts followed Braun and Clarke (2006),

with the researcher (CG) repeatedly reading the data, assigning initial codes and developing similar codes into potential themes. Both analyses were discussed amongst the research team and the results outlined below were agreed.

Results

Twenty-two women were eligible, and 18 (82%) consented (see Table 1).

Overall, 79 goals were identified (mean = 4.38 per participant; range 2–6) (see Table 2). Women's ratings of the importance of each goal ranged from 5 to 10, with 62 (78.4%) rated 9 or above. Ratings were not limited to whole numbers (e.g. 7.5, 9.8 were given), indicating women made fine judgements about the importance of each goal.

Twelve patients and three health professionals (one surgeon, two psychologists) were interviewed. All were overwhelmingly positive about PEGASUS. Thematic analysis identified three themes, briefly described below.

Improving communication in the decision-making process

All patients described PEGASUS as very useful, by helping them prepare for the surgical consultation and clarify their expectations. Both patients and professionals stressed the value of the conversation in eliciting the recorded goals:

It's the dialogue that you have that enables them (patients) to move from a really vague idea of something they might want to achieve into operationalising three or four targeted specific goals with clear, you know, measurable ways in which they will know if it's been successful. (professional 3)

things go round and round and round in lots of different ways depending on how you are feeling. Getting it down on paper is a completely different matter...it forced me to really think about what I was doing. (patient 1)

Women no longer worried they would feel overwhelmed in the consultation, and felt the surgeon was aware of what they wanted to achieve. PEGASUS helped professionals

Table 1. Participant characteristics ($n = 18$).

Age	
Mean (SD)	51.06 years (10.40)
Range	33–77 years
Relationship status	
Married/cohabiting	12 (67%)
Ethnicity	
White/UK	15 (83%)
Diagnosis	
Invasive breast cancer	14 (78%)
Pre-invasive condition (DCIS; ductal carcinoma in situ)	3 (17%)
High risk/family history	1 (5%)
Time since diagnosis	
Mean (SD)	33.41 months (46.41)
Range	1–192 months
Adjuvant treatment (chemotherapy/radiotherapy)	12 (67%)
Breast reconstruction being considered	
Immediate reconstruction	4 (22%)
Delayed reconstruction	14 (78%)

Table 2. Content analysis of 79 breast reconstruction-related goals (as listed by the 18 participants on their completed PEGASUS forms).

Category	Example	<i>n</i>
To <i>look</i> 'normal'	'My reconstructed breast feels natural/looks natural (symmetrical) naked'	15
To be able to wear 'normal' clothes	'I will be able to get dressed in my normal things'	13
To <i>feel</i> 'normal', like other women	'I can feel complete & normal like other women'	11
To avoid using a prosthesis	'I do not have to use a large and heavy prosthesis or worry that it is going to slip'	11
To improve intimate relationships	'I will be less pre-occupied with the left side of my chest during intimacy'	7
To feel feminine	'so that I can restore my sense of femininity'	5
To gain closure on the cancer experience	'I can draw a line under the whole journey'	4
To not restrict physical activity	'there is a minimal impact on my mobility as possible'	4
To feel confident	'I can reinstate my self-confidence'	3
To stop avoidance behaviours	'not having to think about hiding away'	3
To have tried all possible treatments	'Whatever the outcome I would like to know'	2
To be a good role model to others	'I want to be an example to my daughters'	1

focus the consultation around individual needs and expectations and, for some patients, this had increased their confidence in the surgeon:

I trust him now, I really do trust him – because he's honestly said what he thinks. (patient 3)

Health Professionals appreciated its help in identifying exactly what each patient would consider to be a successful outcome:

'It really sort of focuses you on the tangible gains, you know, it's not just that you'd feel better but how would you know you feel better? (professional 3)

Unexpected expectations

Despite having worked in this field for some time, health professionals were surprised by some of the expectations patients specified as being important to them:

I was surprised by the level of investment in the breast for many of the women. (professional)

PEGASUS had successfully enabled participants to express issues that had not been raised with these health professionals in the past. For example, one woman wanted reconstruction in order to be a good role model for her daughters who might also be at increased risk of breast cancer.

Delivering PEGASUS

All the participants met with a psychologist and most thought it might be difficult to complete PEGASUS without this interaction:

It was really helpful to sit down with her as well. It was a bit of an eye opener that one. I think I would have struggled had I been on my own with it. (patient 3)

The psychologists were confident that other health professionals such as trained, experienced specialist nurses would be well-placed to take on this role.

Patient interviews indicated that the PEGASUS sheet was used according to the intervention protocol in 9/12 consultations. However, three women thought that the surgeon paid little attention to the PEGASUS sheet or seemed unsure how to use it.

Discussion

Failure to understand patients' preferences is a common 'misdiagnosis' that warrants interventions to 'transform the role of patients in the NHS from passive users into active and engaged partners in care' (Mulley, Trimble, & Elwyn, 2012, p. viii). PEGASUS aims to achieve this by promoting shared decision-making and understanding of patients' preferences. This preliminary study found it was well received by patients and health professionals alike. Women could explore, identify and rate their personal goals and reported that PEGASUS prepared them for their consultation. The surgeon felt it enabled him to concentrate on each woman's individual goals, which informed shared decision-making.

Our study suggests PEGASUS can facilitate surgeon-patient communication and shared decision-making. Most of the participants' expectations and motivations mirrored those previously reported in the literature, for example a desire to look and feel 'normal' (see Denford, Harcourt, Rubin, & Pusic, 2011; Snell et al., 2010). Yet, some were surprising to professionals who were very experienced in working with this patient group, supporting suggestions that health professionals' understanding of women's priorities around reconstruction could be improved (Lee, Hultman, & Sepucha, 2010).

This study suggests that no changes are needed to the structure of PEGASUS. Although it had not been used as intended in some of the earlier surgical consultations, completion improved as surgeons became accustomed to its use. In the future, specialist nurses may be ideally placed to deliver PEGASUS. It might also be used in conjunction with online decision aids (e.g. Sherman, Harcourt, Lam, Shaw, & Boyages, 2014).

There are some limitations to this small acceptability study. There is a potential self-selection bias amongst the 12 women who agreed to be interviewed. All the participants were treated by the same reconstruction team within a large NHS hospital and most were seeking delayed reconstruction. Future research should explore its use by other teams in different settings and examine, in more detail, its feasibility within the pathway for women contemplating immediate reconstruction. We have not yet assessed its impact on patient-reported outcomes such as satisfaction with decision-making and surgical outcome. Future studies will therefore include relevant self-report measures including longer term outcomes, a comparison group and an economic analysis of its impact on health resources. PEGASUS also has potential with other patient groups.

Disclosure statement

No potential conflict of interest was reported by the authors.

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References

- Abu-Nab, Z., & Grunfeld, E. A. (2007). Satisfaction with outcome and attitudes towards scarring among women undergoing breast reconstructive surgery. *Patient Education and Counseling*, *66*, 243–249.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*, 77–101.
- Caldon, L. J. M., Collins, K. A., Reed, M. W., Sivell, S., Austoker, J., Clements, A. M., ... Elwyn, G. on behalf of the BresDEX Group. (2010). Clinicians' concerns about decision support interventions for patients facing breast cancer surgery options: Understanding challenge of implementing shared decision making. *Health Expectations*, *14*, 133–146.
- Craig, P., Dieppe, P., Macintyre, S., Michie, S., Nazareth, I., & Petticrew, M. (2008). *Developing and evaluating complex interventions: New guidance*. London: Medical Research Council.
- Denford, S., Harcourt, D., Rubin, L., & Pusic, A. (2011). Understanding normality: A qualitative analysis of breast cancer patients concepts of normality after mastectomy and reconstructive surgery. *Psycho-Oncology*, *20*, 553–558.
- Dept. of Health. (2010). *Equality & Excellence: Liberating the NHS*. London: Author.
- Harcourt, D., & Rumsey, N. (2004). Mastectomy patients' decision-making for or against immediate breast reconstruction. *Psycho-Oncology*, *13*, 106–115.
- Krippendorff, K. (1980). *Content analysis. An introduction to its methodology*. London: Sage.
- Lam, W. W. T., Chan, M., Or, A., Kwong, A., Suen, D., & Fielding, R. (2013). Reducing treatment decision conflict difficulties in breast cancer surgery: A randomized controlled trial. *Journal of Clinical Oncology*, *31*, 2879–2885.
- Lee, C. N., Hultman, C. S., & Sepucha, K. (2010). Do patients and providers agree about the most important facts and goals for breast reconstruction decisions? *Annals of Plastic Surgery*, *64*, 563–566.
- Mulley, A., Trimble, C., & Elwyn, G. (2012). *Patients' preferences matter: Stop silent misdiagnosis*. London: King's Fund.
- National Mastectomy & Breast Reconstruction Audit. (2011). *4th annual report*. Leeds: NHS Information Centre.
- Politi, M. C., Dizon, D. S., Frosch, D. L., Kuzemchak, M. D., & Stiggelbout, A. (2013). Importance of clarifying patients' desired role in shared decision making to match their level of engagement with preferences. *BMJ*, *347*, doi:10.1136/bmj.f7066
- Sheehan, J., Sherman, K. A., Lam, T., & Boyages, J. (2007). Association of information satisfaction, psychological distress & monitoring coping style with post-decision regret following breast reconstruction. *Psycho-Oncology*, *16*, 342–351.
- Sherman, K., Harcourt, D., Lam, T., Shaw, L.-K., & Boyages, J. (2014). BRECONDA: Development and acceptability of an interactive decisional support tool for women considering breast reconstruction. *Psycho-Oncology*, *23*, 835–838.
- Sivell, S., Edwards, A., Manstead, A. S. R., Reed, M. W. R., Caldon, L., Collins, K., ... Elwyn, G., & BresDex Group. (2012). Increasing readiness to decide and strengthening behavioral intentions: Evaluating the impact of a web-based patient decision aid for breast cancer treatment options (BresDex: www.bresdex.com). *Patient Education and Counseling*, *88*, 209–217.
- Snell, L., McCarthy, C., Klassen, A., Cano, S., Rubin, L., Hurley, K., ... Pusic, A. (2010). Clarifying the expectations of patients undergoing implant breast reconstruction: A qualitative study. *Plastic and Reconstructive Surgery*, *126*, 1825–1830.
- Stacey, D., Kryworuchko, J., Bennett, C., Murray, M. A., Mullan, S., & Legare, F. (2012). Decision coaching to prepare patients for making health decisions: A systematic review of decision coaching in trials of patient decision aids. *Medical Decision Making*, *32*, E22–E33.
- Stevenson, F. A., Cox, K., Britten, N., & Dundar, Y. (2004). A systematic review of the research on communication between patients and health care professionals about medicines: The consequences for concordance. *Health Expectations*, *7*, 235–245.