

Supplying Women with Evidence Based Information

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Summary of project

NHS consumers need accurate, accessible, evidence based information from which to make decisions about their care. However, consumer involvement in designing and disseminating this information is greatly neglected. At Liverpool Women's Hospital, a working group has met monthly since 1997 to formulate and update Recommended Best Practice Guidelines (RBPs). However, there was no consumer input in this process and, therefore, any problems encountered occurred when the RBP had already been introduced. This benefited neither the practitioner nor the woman.

This project formed a group comprising consumers and a midwife researcher to rewrite the existing hospital RBPs in a format appropriate for the consumer. Over a twelve month period, twenty-four women from diverse backgrounds have been involved. The consumers have decided which RBPs are appropriate for the project and

the group has rewritten these removing all medical terms and inappropriate information. A prospective audit of the effectiveness of this information has been carried out using consumer and staff questionnaires. The information sheets have been amended in line with consumer suggestions. These are now available in the clinical areas. The RBPs are to be reviewed every two years, or when new evidence becomes available. The information sheets will be updated to reflect these changes.

Background

Over the last decade the issues of choice and informed consent have dominated the midwifery press, with the policy agenda for maternity care prioritising 'women-centred' services (Welsh Office, 1991; Department of Health, 1993). Pivotal to this approach is the provision of appropriate information on which women can base their childbirth decisions. Various methods are used in maternity units to disseminate information. However, maternal views on the suitability of this information are inconclusive.

Research has discovered a wide discrepancy between the childbirth educator's agenda and that of the women in her care (Schott, 1994), with women often requiring more realistic information than is provided (Hillan, 1992). The report Changing Childbirth (1993) raised awareness of pregnant women's needs for information, an issue which was subsequently highlighted in the national survey, First Class Delivery (1997). In this survey, practitioners were warned not to underestimate the value that pregnant women place on information about their own and their babies' well being.

In a local study of the management of prolonged labour (Lavender, et al 1999) it was evident that many women felt reassured that practices were based on evidence. However, although there has been a recent emphasis on making women 'Partners in Research' (Kenyon, 1997), there has been minimal activity to enable women to become partners in disseminating information.

EVIDENCE

One of the main objectives of the NHS Research and Development Strategy is 'to ensure that the benefits of research are systematically and effectively put into practice' (Department of Health, 1993). Consumers can play a pivotal role in ensuring this objective is met, a factor which has recently been highlighted with the introduction of Clinical Governance (NHSE, 1999). An advisory group which assessed consumer involvement in the NHS R&D programme (Standing Advisory Group on Consumer Involvement, 1998) stated that consumers' views are central to the concept of quality of life, to the relevance of outcome measures and to decisions about health care. Furthermore, this group emphasised the fact that 'as stakeholders in the NHS' consumers have a right to be involved in decisions about health care.

Project Outline

The project formed a group called the Women's Information Network (WIN) to rewrite the existing hospital RBPs in a format appropriate for the consumer. The group met monthly and comprised six consumers and a research midwife.

A diverse group of consumers was recruited, and each participant was invited to attend a maximum of three meetings to provide some continuity for the women, whilst ensuring a diversity of participants overall. In total, twenty-four consumers who had a variety of maternity experiences were involved in the project.

They were recruited in several ways and from a diversity of backgrounds:

- Women from ethnic backgrounds were invited by contact with the local ethnic group link department at the local health centre. A link worker attended each meeting, again for a maximum of three meetings.
- A specialist midwife who co-ordinates the hospital teenagers' antenatal clinic provided a valuable contact for the recruitment of teenagers.
- A member of the National Childbirth Trust (NCT) was approached via a local branch.
- On occasions, women were approached whilst they were in-patients at the hospital.

The consumers decided which of the existing RBPs were appropriate for consideration by the group. The titles of those that were selected are shown in Box 1.

Box 1. Titles of RBPs

Management of first stage of labour
Management of second stage of labour
Management of third stage of labour
Dysfunctional labour
Hypertension – management as an outpatient
Hypertension – management as an inpatient
Fetal heart monitoring in labour
Management of women who are Group B
Streptococcus carriers
Perineal repair/perineal damage
Retained placenta
Vaginal birth after caesarean section
Waterbirth
Pain relief in labour
Skin to skin contact for breastfeeding
Elective and emergency caesarean section
Assisted vaginal delivery
Breech presentation in labour
Breech presentation in late pregnancy

Research midwives were seconded to the project to review the existing RBPs and condense them into a format that was more appropriate for the consumer group. Progress with this work was fed back to the consumer group on a monthly basis. Rewriting the documents proved to be more challenging than first anticipated as the research midwives have fifteen years of medical jargon firmly ingrained in their vocabulary. On occasions, when simple translations were difficult, illustrations were used. The consumers confirmed that this approach proved to be invaluable. If there was any doubt about the content and relevance of information that was included in the information sheet, the consumers made the final decision.

Evaluation

An audit of the eighteen RBPs was carried out between February 1st 2002 and July 31st, 2002. Six topics of information were displayed each month in all the maternity wards and clinic areas within the Trust. The information sheets were copied, with an audit sheet attached, and were made distinguishable by placing them in separate display stands. Posters explaining the intent of the project and the audit supported the displays. The posters invited both women and members of staff to complete the audit sheets and post them in collection boxes.

The information collected through this audit were subject to both qualitative and quantitative data analysis. The

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qualitative data were transcribed from the audit tool and re-read many times. Categories were identified and themes emerged from each category. The quantitative data was input into SPSS software and analysed using descriptive statistics.

Findings

In total, 168 questionnaires were completed. All of the information sheets had been read and commented on by the audit participants.

Profile of respondents

- The majority of respondents were multigravida women
- Most had read the information sheets during the antenatal period
- The median gestation when the sheets were read was 32 weeks (range 12-42 weeks)
- Of the postnatal women who completed questionnaires, the median time of reading the information sheets was 3 days after delivery (range 1-9 days)
- The postcode sample was varied and included women from both deprived and affluent areas
- The majority of women were aged between 31-40.

Quantitative findings

- The most frequently read information sheets were those relating to labour
- 83.1% of respondents had no difficulty in finding pregnancy related information
- 70.6% of respondents had access to the internet and would use it to access information
- The information sheets were found to be of some use (11.9%), useful (50.6%) or extremely useful (36.9%)
- 95% of respondents found the information sheets extremely easy to read, although a small number of women (12.5%) suggested that some words or phrases should be changed.

Qualitative comments

Three qualitative categories emerged:

- Amendments – this included themes about the layout and content of the information sheets
- Feedback – the majority of comments within the category were positive, however, a minority were negative
- Logistics – this included themes of timing and location. For example, one woman suggested that the information sheet for caesarean section

should be given in the antenatal period if this mode of delivery was considered and there were some suggestions that displays in outside of the wards areas such as pharmacy and ultrasound should also be considered

Discussion

The women involved in the WIN groups reported that they enjoyed being involved in a project that was successful in developing user-friendly information for other women. For some women whose opinions may otherwise have been unheard, their involvement in groups that were both diverse and dynamic was an empowering experience. Such an approach embraces the philosophy of clinical governance by ensuring consumer involvement.

Whilst there is evidence that indicates decision aids improve knowledge, reduce decisional conflict and stimulate consumers to be more active in decision making without increasing anxiety (O'Conner et al., 1999), it must be recognised that contradictory evidence also exists which suggests that information leaflets are not effective in promoting informed choice for women using maternity services (O'Caithain et al., 2002). In view of this, the limitations of this project need to be considered.

Although the women who took part in the WIN project were not involved in creating the original RBPs, they were involved in re-writing the recommended best practice guidelines that were currently in use to inform practice within the study hospital. This ensured that the information on the sheets was relevant to the settings in which these women received their care, in comparison with the leaflets that were considered in the study by O'Caithain et al (2002). However, this project does not seek to indicate whether women are better informed as a result of reading the information sheets and it does not find out if information written in this way creates a foundation that would support a more informed decision making process. These aspects should be considered for future research.

Because the project was evaluated using a pragmatic audit, information sheets were not distributed to all women using the maternity services. Instead, the information was made available and accessible to women in all maternity ward and clinic areas, reflecting a real life setting. Although the postcodes of the respondents varied, and incorporated women from underprivileged areas, together with women from a more affluent environment, it is recognised that the majority of respondents were more mature women. It would be

interesting to explore the opinions of a larger sample of younger women in future audits.

Bekker et al (1999) suggest that the way information is presented can affect decision-making. The qualitative responses to this evaluation support this view, as the women felt that information should be made to 'stand out' when displayed. Within their systematic review, Bekker et al (1999) also found that it was those studies which had altered the delivery of information and included the provision of feedback that were more likely to report an effect. This may explain the overwhelming positive response generated from this project both because it was based upon the ethos of manipulating medicalised jargon, and because the women fed-back throughout the process.

The majority of respondents stated that they had access to, and would use, the internet to gain information. This will support the introduction of the information sheets onto the hospital intranet. Despite the positive response to internet usage that was generated from this project, an important consideration should be gained from one qualitative comment. This viewed the internet as a dangerous and more confusing mode of accessing information, especially if searched in a haphazard way where information discovered for a specific question. Professionals need to be mindful of the importance of providing valid and reliable information via the internet (Allum and Mersey, 2002), an approach which is supported by this project.

Conclusion

The women involved in this project enjoyed being part of diverse and dynamic groups that were responsible for formulating information for other women. The group status was an empowering experience for some women whose opinions may otherwise have been unheard. The results indicated that information generated using this method embraces the philosophy of clinical governance that ensures consumer involvement.

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