Quality Improvement in a Maternity Ward and Neonatal Intensive Care Unit

What are staff and patients' experiences of Experience-based Co-design?

Part 1: A qualitative study

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Abstract

Background: Recent focus on quality and patient safety has underlined the need to involve patients in improving healthcare. "Experience-based Co-design" (EBCD) is an approach to capture and understand patient and staff (i. e. users) experiences, identifying so called "touch points" and then working together equally in improvement efforts.

Purpose: This article elucidates patient (defined as the mother-newborn couple with next of kin) and staff experiences following improvement work carried out according to EBCD in a maternity ward and neonatal intensive care unit (NICU) in a small, acute hospital in Sweden.

Method: An experience questionnaire, derived from the EBCD approach tool set, was used for continuously evaluating each event of the EBCD improvement project. Furthermore, a focus group interview with staff and in-depth interviews with mother-father couples were held in order to collect and understand the experiences of working together according to EBCD. The analysis and interpretation of the interview data was carried through using qualitative, problem-driven content analysis. Themes, categories and sub-categories presented in this study constitute the manifest and latent content of the participants' experiences of Experience-based Co-design.

Results: The analysis of the experience questionnaires, prior to the interviews, revealed mostly positive experiences of the participation. Both staff and patient participants stated generally happy, involved, safe, good and comfortable experiences following each event of the improvement project so far.

Two themes emerged during the analysis of the interviews. For staff participants the improvement project was a matter of learning within the microsystem through managing practical issues, moving beyond assumptions of improvement work and gaining a new way of thinking. For patients, taking part of the improvement project was expressed as the experience of involvement in healthcare through their participation and through a sense of improving for the future.

Discussion: This study confirms that, despite practical obstacles for participants, the EBCD approach to improvement work provided an opportunity for maternity ward /NICU care being explored respectfully at the experience level, by assuring the sincere sharing of useful information within the microsystem continuously, and by encouraging and supporting the equal involvement of both staff and patients. Staff and patients wanted and were able to contribute to the EBCD process of gathering information about their experiences, analyzing and responding to collected data, and engaging themselves in improving the same. Furthermore, the EBCD approach provided staff and patients the opportunity of learning within the microsystem. Nevertheless, the responsibility of the improvement work remained the responsibility of the healthcare professionals.

Keywords: Quality Improvement, Maternity Care, Neonatal Intensive Care, Experience-based Co-design

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Introduction

Patient participation in improvement work

Strengthening the role of patient participation has been identified as an important factor in improving healthcare. The recent focus on quality and patient safety has further underlined the need to involve patients. Patients carry valuable experiences of the healthcare system that can contribute to further research and safer care. Patient participation is therefore an important resource in improvement work, not the least in obstetrics and neonatal intensive care (Johnson et al., 2008; Scholefield, 2008). Not only patients, but carers, parents or other people who plead on behalf of the sick and vulnerable should have input to healthcare services, and they should be involved in the design of those services (Greenhalgh, Humphrey & Woodard, 2011).

Bate and Robert (2007a) discusses enhancing patients' and users' influence by introducing "Experience-based Co-design". Co-experience is experience created in social interaction. It is a process where participants together contribute to the shared experience in a reciprocal way, creating interpretations and meanings from their life context and thus allowing themes and social practices to evolve. Co-experience is driven by social needs of communication and maintaining relationships as well as creativity in collaboration (Battarbee, 2003). Experience-based Co-design is an approach to capture and understand patient and staff (i. e. users) experiences, identifying so called "touch points" i.e. critical moments, experiences or turning points and then working together to improve them. The objective is to make patient and staff experiences play a major role in the development and redesign of healthcare. The understanding of how users feel and experience certain situations can lead healthcare towards significant enhancements, resulting in positive experiences and new learning. Experience-based Co-design is also about patients and staff working together equally in improvement efforts. Instead of having a consulting role both parts will contribute with their respective experiences in designing improvements and new solutions, making it more fit for the purpose. This approach can lead to meaningful and lasting improvements in safety, efficiency, dignity and reliability of health services (Bate & Robert, 2006; Bate & Robert, 2007a; Bate, Mendel & Robert, 2008; Maher & Baxter, 2009). Furthermore, Bate and Robert argue for a major shift from the strong management focus on organizational development (OD) to a more user focused approach that prioritizes change on behalf of the users, involving them at every stage of the design process, from identifying problems to solution finding and implementation (Bate & Robert, 2007b).

User involvement in the health sector has a long history in the National Health Service (NHS) in United Kingdom, formally beginning in the 1970s. A list of beneficiaries to NHS, people, public health, communities and society as a whole, set out the UK government's strategy to support public involvement in the NHS. The publication "The experience-based design approach. Experience based design. Using patient and staff experience to design better healthcare services. Guide and tools" is one of many quality and service improvement tools, theories and techniques provided by the NHS Institute for Innovation and Improvement (NHS Institute for Innovation and Improvement, 2009). However, a number of issues and challenges common to efforts to involve patients and staff in co-design have also been observed. It is about attracting a representative cohort of users (e. g. staff and patients), making involvement achievable and worthwhile, preparing staff and patients, identifying problems, generating and selecting potential solutions and finally achieving closure (Greenhalgh et al., 2011). Davis, Jacklin, Sevdalis and Vincent also point out limitations and possible dangers on patient involvement in healthcare. Patients can act as "safety buffers" and contribute to their care, but the responsibility for their safety must remain with the healthcare professionals. Patients should only be involved when they want and are able

to. Schwappach, (2010) implies that patients share a positive attitude about being engaged in their safety at a general level, but their intention and actual behaviour vary considerably. Furthermore, user involvement may not automatically lead to improved service quality. Staff and patients understand and practice user involvement in different ways according to individual ideologies, circumstances and needs. If health professionals determine how patients will be involved it may limit change that can be achieved (Fudge, Wolfe & McKevitt, 2008).

The work of Bate and Robert and NHS has drawn some attention in Sweden, and The Swedish Association of Local Authorities and Regions (2011) has published a modified translation of the Experience-based Co-design approach.

Patient experiences of participation in neonatal intensive care

Several Swedish studies with qualitative approach describe the mothers' experiences in connection with their newborn babies being cared for in a neonatal intensive care unit (NICU) (Erlandsson & Fagerberg, 2004; Nyström & Axelsson, 2002; Wigert, Johansson, Berg, & Hellström, 2006). To be separated from her newborn baby has been shown to be one of the most difficult things a mother experiences. Her experiences pendulate, according to Wigert et al. (2006), between a sense of being completely involved in the care of herself and her baby and a sense of being totally left-out. Erlandsson and Fagerberg (2004) describe the mother's strive to be close to her baby regardless of circumstances. Examples of experiences expressed include the perception of the hospital's organization and procedures, staff routines and other circumstances which may prolong the time the mother is separated from her baby. It has been proposed that a so called "Humane Neonatal Care Initiative" should be launched. The Humane Neonatal Care Initiative focuses on the psychological needs of the sick and premature newborn baby, and one of the eleven steps included advocates for giving the mother an opportunity to stay in the NICU with her baby 24 hours a day (Levin, 1999).

Newborn, healthy babies react negatively when separated from their mothers. Babies cared for in a cot cried significantly more than babies cared placed skin-to skin to their mothers (Christensson, Cabrera, Christensson, Uvnäs-Moberg & Winberg, 1995). Moreover, the environment for preterm and sick babies in the NICU is much more complicated than for healthy babies cared for in the maternity ward. Technology, medical advances and improved caretaking procedures have resulted in significant increase in neonatal survival, but the NICU environment can be an extremely noisy and stressful place for both babies and their parents. Premature babies in particular are unable to filter out or ignore stimuli in the same way as full-term babies. Developmental care as defined in the "Newborn Individualized Developmental Care and Assessment Program" (NIDCAP®) emphasizes the behavioural individuality of each newborn preterm and sick baby. It is about nurses, families and physicians jointly working to plan and implement individualized care and environments supportive of each baby and it seeks to reduce the baby's experiences of stress and to enhance its' strengths. The NIDCAP® care model has been implemented in many NICUs and successfully evaluated in a number of studies (Als et al., 2002).

Progress has been made towards unrestricted presence of parents and other next of kin in the NICUs. The philosophy of "Family-Centred Care" (FCC) highlights the central role that the parents and significant others have in a child's life and outlines practices, policies and programs that support the family. The foundation to FCC is the partnership between families and professionals (Reis, Scott & Rempel, 2009). However, even though parental participation has been highly recommended from the research side for many years in the European NICUs, most mothers (with next of kin) are still separated from their babies during the major part of the hospital stay and many parents experience their encounter with health professionals as a struggle characterized by

the uncertainty of their roles (Fegran, Helseth & Slettebø, 2006; Greisen et al., 2009). In addition, parents must live with the consequences of the decisions they make with the NICU staff, and the consequences may not be apparent for a long time after a decision has been made (Yee & Ross, 2006). Thus NICUs should review their policies and find ways to promote parent participation (Greisen et al., 2009). Providing facilities for parents to stay in the NICU 24 hours a day, from admission to discharge, may reduce the total length of stay for prematurely born babies. An individual-room NICU design could also have a direct effect on the stability and morbidity of the baby (Örtenstrand et al., 2010).

Staff experiences of parent participation in neonatal intensive care

From being concerned primarily with a baby's physiological and medical condition, nurses today are strongly aware of each baby's various and complex needs, not least the importance of baby-parent attachment (Fegran et al., 2006). But variable patient interest, health professional attitudes and lack of insight on appropriate methods may limit patient involvement (Fudge et al., 2008; Gagliardi, Lemieux-Charles, Brown, Sullivan & Goel, 2008). The ethical demand for nurses is to reflect on their competence and willingness to involve parents in the care of their baby to an extent and in areas jointly determined by parents and staff (Fegran et al., 2006). Ensuring that parents have good information on which to base their decisions requires intense effort from staff using innovative communication strategies. Information should be consistent from all health professionals, understandable, often repeated and tailored to the individual parents. Equipping staff to undertake the communication strategies suitable should be a mandatory part of their training, and its practice should be a compulsory part of the care (Yee & Ross, 2006).

Local problem

This study was performed in a maternity ward and NICU at a small acute hospital situated on the east coast of southern Sweden. The problems which follow organizational and professional boundaries created within the maternity ward/NICU microsystem (the term microsystem is defined below) had been observed by the staff in the setting. Because of this, a team consisting of staff members from the maternity ward and the NICU collaborated with a focus on creating a common maternity and neonatal care and working on organizational issues associated with it. Members of the team included an obstetrician, midwives and children's nurses from the maternity ward and pediatricians, pediatric nurses and children's nurses from the NICU. The purpose was to increase communication and interprofessional practice between the care providers, in benefit for both staff and patients. However, so far the patients (defined as the mother-newborn couple with next of kin) had not been represented in this team. Because of this there was a lack for knowledge about the care given and improvement efforts needed, and a non-ending row of patient complaints had reached the organization. Thus, improvement efforts without including the patients seemed not to solve the problems following organizational and professional boundaries within the maternity ward/NICU microsystem.

Intended improvement

The clinical microsystems are the smallest, patient near, replicable units of the healthcare system. In these systems, patients and health professionals work together, creating the value of healthcare. A seamless, patient-centred, quality safe and efficient healthcare system can not be created without the development of these microsystems. High-performing microsystems are created through continuous, sustainable improvements (Nelson, Batalden & Godfrey, 2007; Nelson et al., 2008). Up to now, evaluative research of implementing a clinical microsystem approach in the

NICU has primarily focused on staff perceptions and satisfaction. Using a clinical microsystem approach in the maternity ward/NICU requires careful attention to the parents and their experience of their own and their newborn babies' care. It is only by evaluating the experiences of the parents as equal partners that optimal healthcare can continue to evolve in the maternal ward/NICU microsystem (Reis et al., 2009).

The microsystem involved in this study is the healthcare situation where a mother (with next of kin) is a patient in the delivery and maternity ward and her newborn baby is a patient in the NICU. Interviews have shown that the mother experiences her stay in the hospital as one continuous event and does not distinguish between departments or ward staff in the delivery and maternity ward or NICU (Erlandsson & Fagerberg, 2004). Thus, the microsystem in this case involves the patient (defined as the mother-newborn couple with next of kin), staff in the maternity ward (obstetricians, midwives and children's nurses) and staff in the NICU (pediatricians, pediatric nurses and children's nurses).

Experience is an extremely valuable source of knowledge, through which we are able to identify those parts of health services where the patients' feelings, positive and negative, are being most strongly formed. These experiences can be put into words and defined as so called touch points, which can guide to where improvement efforts need to be focused. Improvement teams consisting of staff and patients can jointly redesign the system to improve services for future patients. Making improvement efforts by enhancing patient participation in the maternity ward/NICU microsystem is also a way to strengthen cooperation and learning within the local microsystem, and provide an opportunity for the microsystem to develop into a high-performing healthcare system (Bate & Robert, 2006; Bate & Robert, 2007a; Bate, Mendel & Robert, 2008).

The purpose of the improvement project carried out in this study was to improve healthcare experiences for staff and patients by jointly identifying and improving experiences according to Experience-based Co-design (EBCD) in the maternity ward/NICU microsystem. The questions for the improvement project were formulated as follows:

- What are the touch points identified by staff that are not touch points identified by patients?
- What are the touch points identified by patients, that have not been perceived as touch points by staff?
- What are the touch points identified as areas for improvement by both patients and staff?
- What are the results of the improvement work carried out jointly by patients and staff? (Results reported in Part 2.)

Study question

The aim of the study was to describe patient (defined as the mother-newborn couple with next of kin) and staff experiences following improvement work carried out according to Experience-based Co-design (EBCD) in the maternity ward/NICU microsystem.

Methods

Ethical issues

The improvement work and the study of the improvement work were formally approved by the Research Ethics Committee at The School of Health Sciences in Jönköping, Sweden, and by the managements at the Department of Gynecology and the Department of Pediatrics in the local hospital setting.

In line with the principles of good practice and relevant data protection legislation, information from the improvement work and the study was kept electronically on a password protected computer server only available to the author of the study. All other study material such as recorded material, memory sticks and questionnaires were securely stored in a locked, fire-safe cabinet situated in a locked room at the local setting. Only the author and the secretary involved in the study had access to the cabinet.

All participants were given verbal and written, detailed information and were given the opportunity to discuss any issues in need for clarification. When the necessary information was given, the participants were asked to sign a consent form. The information collected through interviews could be derived to individuals. Confidentiality was assured in producing the statements by replacing names with terms as him/her/the baby/the mother/the father.

The study participants consisted initially of three patients (mother-newborn couples with next of kin) and eight staff members. To minimize dependency between patients and staff, the improvement work began after the patients' discharge from the maternity ward and NICU. No risk of physical injury was anticipated, but ward counselors were informed about the improvement project in case support was needed.

Interviews, questionnaires, feedback sessions and camera documentation could theoretically pose a risk for privacy intrusion. Through clear, repeated verbally and written information and by respect for the study participants' choice regarding consent to participate in all study areas, the risk of privacy intrusion was minimized.

Feedback sessions in the improvement process were seen as opportunities for participants to correct inaccurate information from the interview analysis and to do additional work to make touch point findings fit their view. The focus of the improvement process was to make participants collaborate on equal terms.

The risk of physical injury and integrity intrusion for participants was considered very small while the benefit was considered to be significant. The fact that the patients before the study started, and perhaps in future healthcare contacts, would be dependent of the participating health professionals was considered during planning for the study. This was expected to be overcome by repeated information and communication along with the joint improvement efforts. Benefits were therefore expected to exceed any risks.

Setting

The setting of the study was a small, progressive hospital situated on the east coast of southern Sweden serving the citizens in the north of Kalmar County. Despite its size, it is a high-performing acute hospital with some of the best clinical outcomes in the country. Several specialist services have national reputation in clinical quality, customer satisfaction, staff satisfaction and financial performance. The hospital has 160 beds, performs 172,500 healthcare treatments every year and employs 1,100 people. The hospital's vision is to be "The innovative emergency hospital with the leading performances". Customer access, patient safety and improvement work are prioritized areas of work (Landstinget i Kalmar län, 2012).

The delivery department consists of the labour ward and the maternity ward adjoined. About 800 children are born in the clinic every year. The labour ward has four rooms for mothers in active labour and one room for women who have an underlying medical condition or need monitoring before and after birth. Adjacent to the labour ward there is an operating theatre for planned and emergency surgery. The maternity ward has 10 beds and cares for women admitted to hospital for closer monitoring during pregnancy and for mother-baby couples in post partum care. In most cases, the maternity ward is able to accommodate the father or other next of kin together with the mother if wished for. Obstetricians, midwives and children's nurses work in the unit.

Children's services include a NICU which provides intensive, high dependency and special care for prematurely born babies as well as sick newborns. Babies as premature as 30 weeks gestation are cared for. The unit has five cots and cares for about 120 newborns every year. The NICU is situated on the floor above the labour ward with a staircase and elevator connecting the two floors. Rooming in for the mother with next of kin is encouraged if possible and two-three rooms are prepared for accommodating them. Pediatricians, pediatric nurses and children's nurses work in the unit.

The delivery department and the NICU work closely with a University Hospital regarding obstetrical medical conditions, premature babies and newborns with a variety of medical and surgical problems.

Planning the intervention

The intervention was planned and designed according to the Experience-based Co-design (EBCD) process. Figure 1 illustrates the process as employed in the case study of using an EBCD approach in a pilot study carried out over a 12-month period with head and neck cancer patients, carers and staff in one acute hospital in England. The EBCD piloted involved gathering experience-related data from patients and staff, verifying the data with them, identifying the so called key touch points to describe improvement areas, joint discussion of those improvement areas (staff and patients together in co-design teams) and finally moving towards implementation and practical action (Bate & Robert, 2007a).
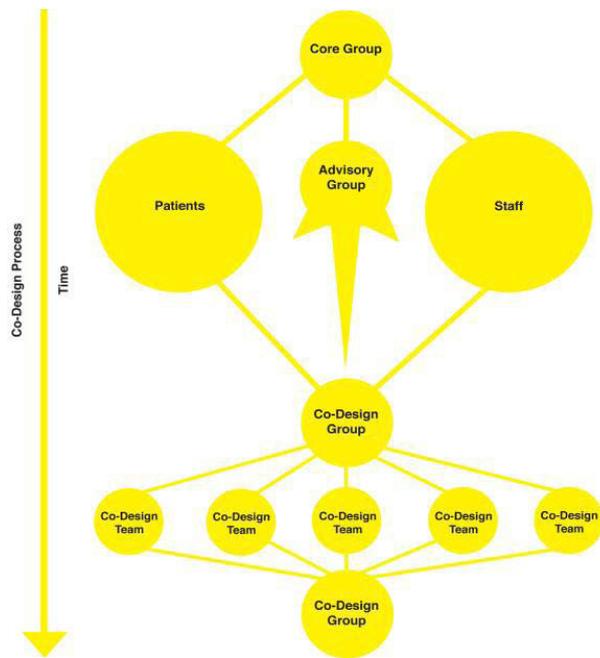
Figure 1: The Experience-based Co-design process (Bate & Robert, 2007a).

The process of the improvement work carried out in this study was designed in a similar way, as illustrated in figure 2. The core group consisted of the improvement leader (the author of this article) coached by a process and development consultant (PDC) working in the particular hospital involved and two academic tutors. In addition, the process carried through in England included an advisory group (see figure 1) made up of patient and carer volunteers plus hospital staff, and their role was to "advise, encourage and warn" (Bate & Robert, 2007b, p. 48). In this present case, the improvement leader (CB) possessed the full background knowledge about the services from working in the setting and was familiar to the department managements in question. Thus, contextual advice and guidance was not presumed to be needed.
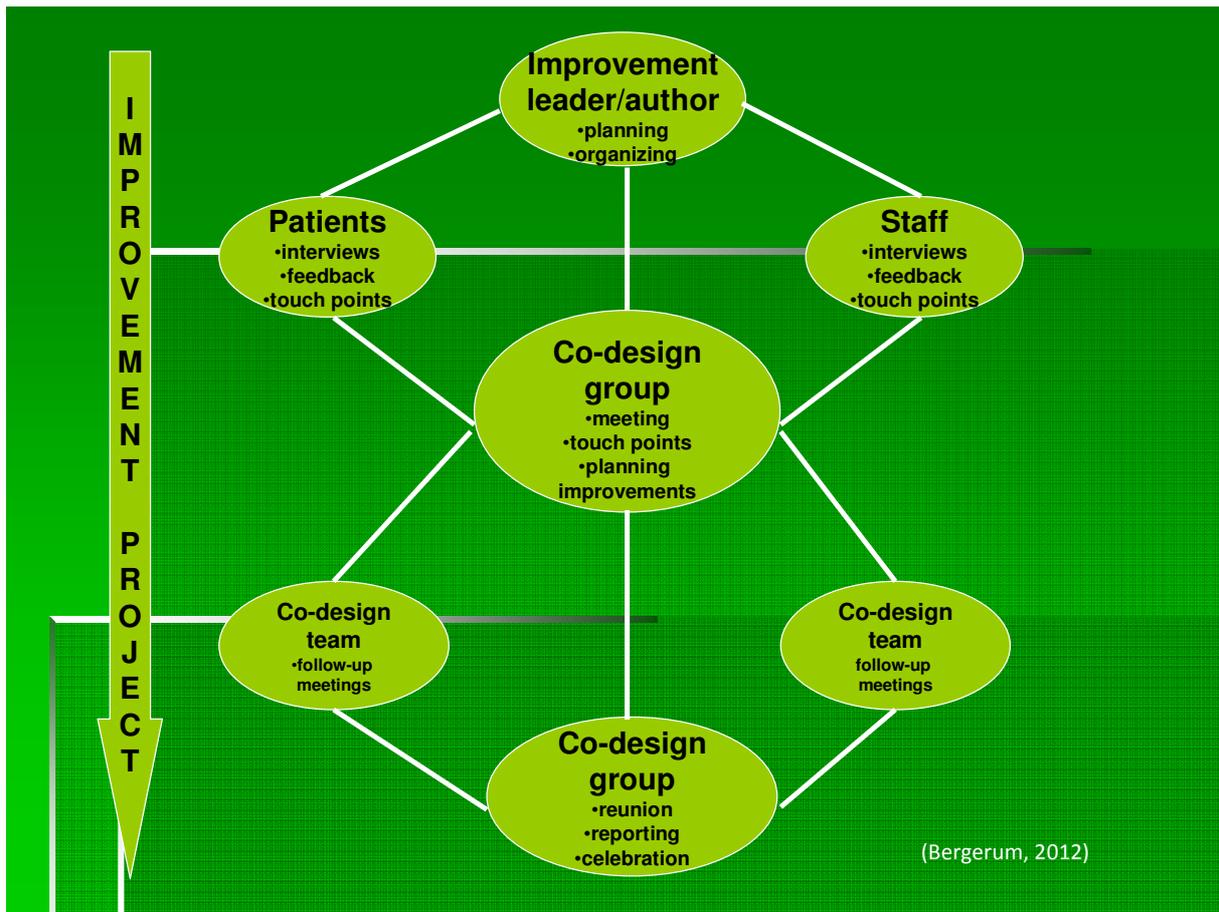
Figure 2: The process of the healthcare improvement work according to Experience-based Co-design in the maternity ward and neonatal intensive care unit.

The intervention and its component parts can in sufficient detail can be described as follows.

September 2011

Information was given to health professionals, patients and managements at the Department of Gynecology and the Department of Pediatrics, as well as to the PDC and the academic tutors. Written consent to carry through with the intervention was given by the department managements. Ethical considerations were made. Practical issues were solved. Written information about the improvement project was exhibited to patients (mothers with next of kin) in the NICU.

October 2011

The staff concerned was invited to participate in the project and their consent was gained. A total of eight members of staff (four from the maternity ward and four from the NICU) agreed to participate. Staff experiences were collected through individual, in-depth interviews. The analysis of staff interviews began, in order to identify touch points.

November 2011

Patients were invited to participate through written information following a telephone contact, and their consent was gained. Three mother-father couples agreed to participate. Patient experiences were collected by in-depth interviews with each mother-father couple. Interviews took place in the patients' homes with only CB present. The analysis of patient interviews began, in order to identify touch points.

The analysis of the staff interviews was completed by CB and the staff feedback session was held on the 22nd of November. This feedback session was led by CB and the PDC, and documented by photographing. Because only five out of eight staff members were able to participate on this occasion, an additional feedback session was held on November 29th with two more staff participants. Touch points were identified, discussed, corrected and completed as a result of these feedback sessions. Each staff member validated the findings and voted (using five individual votes) for the most important touch points to do further work on.

December 2011

The analysis of the patient interviews was completed by CB.

January 2012

A feedback session with the patients was held on the 4th of January. This feedback session was also led by CB and the PDC, and documented by photographing. Due to temporary sickness and accidental oblivion, only one of the three mother-father couples attended the meeting. Nevertheless the session was held according to the original plan. Touch points were discussed and the mother-father couple present validated the findings and voted (using five individual votes) for the most important touch points to work further on. The mother-father couples missing were informed by telephone and through written information, and voted in the same way as the other participants for the most important touch points. This process was completed prior to the co-design group meeting.

The co-design group meeting, which gathered staff and patients, was arranged on the 18th of January. It was led by CB and the PDC, and also documented by photographing. Again due to sickness, one mother-father couple did not attend the meeting. Two staff members were also absent due to illness and one staff member was not able to participate because of high workload. During this event staff and patients discussed the findings separately at first, and then moved to discussing the findings together. It was a lively discussion, and they jointly agreed on two common improvement areas to work further on in the improvement project. For each improvement area agreed on, a co-design team consisting of staff and patients was formed and action plans for the further work were formulated. Staff was given an introduction to the theory of the Model for Improvement (Langley et al., 2009), methods and tools of improvement work by the PDC and at the end of the meeting this introduction was repeated both verbally and in writing to both staff and patients.

January – May 2012

Following the co-design group meeting, the improvement work began. The two co-design teams were coached by CB and the PDC. During the initial improvement work in January - May, three follow-up meetings were arranged to gather all co-design team members.

At the first follow-up meeting on the 8ᵗʰ of March, also led by CB and the PDC, not much improvement work was done in the teams. Teams had begun getting to know each other and had initiated a discussion on their improvement areas. Due to sickness and work, only one parent of the two remaining participating families attended the meeting. Among the participating seven staff members, one was absent because she had recently given birth. Participants attending the meeting were given feedback by results from the introductory analysis of the experience questionnaires. The introduction to the methods and tools of improvement work was repeated and teams were coached to alternative ways of addressing their issues and getting started. Information about the meeting was given to all participants by mail and e-mail a few days later.

During the second follow-up meeting, on the 19ᵗʰ of April, time was spent for evaluating the improvement project so far. Because of illness, one staff member was missing. Six out of seven staff members attended the meeting and the focus group interview. Again due to work, only one parent of the two participating families was able to come. One of the two teams had started their improvement work whilst the other still was still struggling with difficulties. Teams were coached to finding ways for progress in their work. Information about the meeting was given to all participants by mail and e-mail a few days later.

Prior to the third follow-up meeting, which was held on the 23ʳᵈ of May and led by CB and the PDC, transcripts of the interviews were distributed to all participants. Because of illness and high workload, four staff members attended the meeting. No parents were present due to illness and working commitments/travelling distance. Participants present at the meeting had read the transcripts and verified its' contents. The preliminary results from the content analysis were presented and discussed. Both improvement teams were now clear about what they were trying to accomplish, and one of the teams had started running their first cycle to test their improvement strategy. Ideas for further cycles were discussed. A problem for the improvement teams was the oncoming summer season, with staff holidays and for that reason staffing problems at both departments. It was agreed to await further actions in the improvement teams, and a date for a start-up meeting in September was decided on.

Planning the study of the intervention

The purpose of this research was to describe patient (defined as the mother-newborn couple with next of kin) and staff experiences following improvement work carried out according to EBCD in the maternal ward/NICU microsystem.

The study of the intervention, that followed the intervention throughout the process, was planned and conducted as illustrated in figure 3.
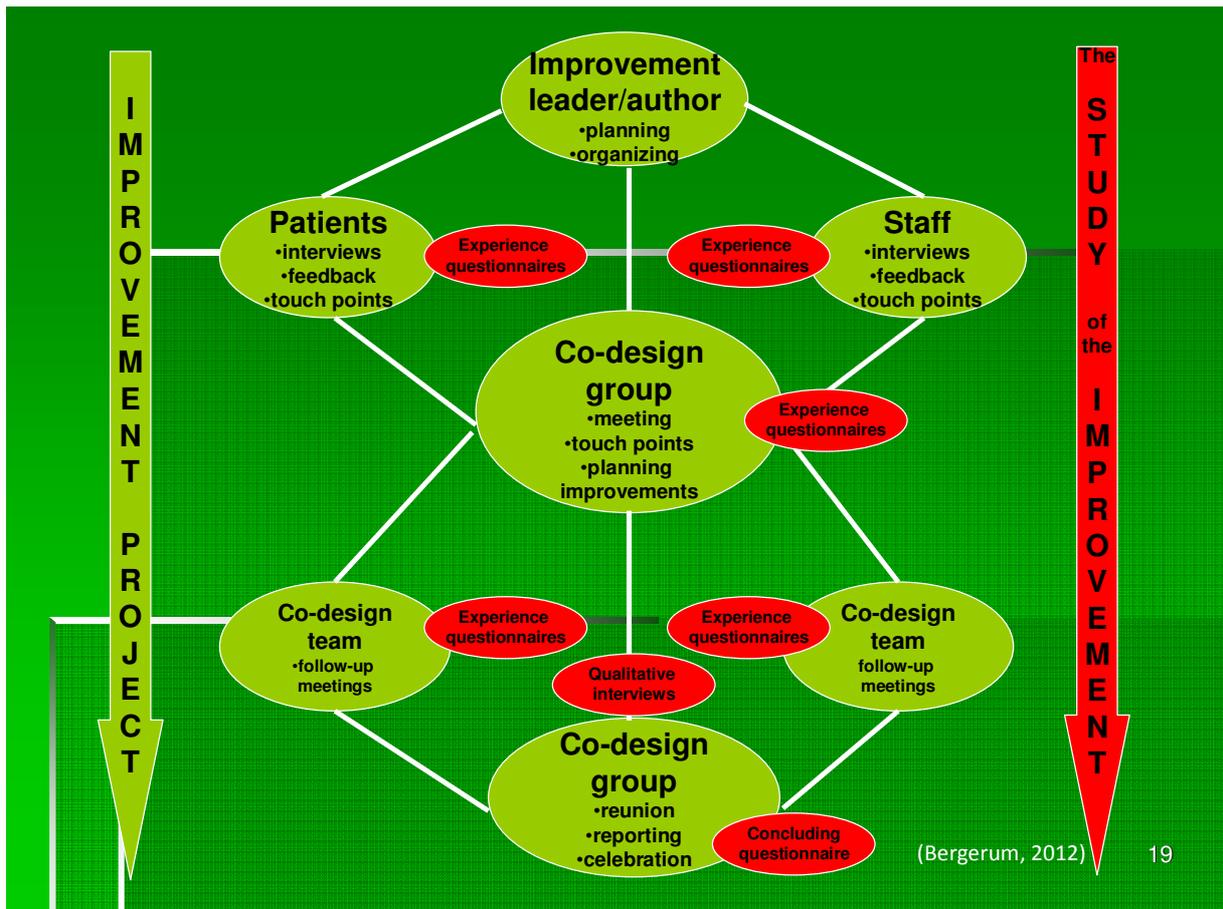
Figure 3: The process of the study of the healthcare improvement work according to Experience-based Co-design in the maternity ward and neonatal intensive care unit.

The improvement leader of the intervention was also the author studying the intervention (CB), coached by two academic tutors at the Jönköping Academy for Improvement of Health and Welfare. The experience questionnaires developed by NHS was used (NHS Institute for Innovation and Improvement, 2009) for continuously evaluating the improvement project (see "Data collection and analysis"). The idea was that results from the analysis of the experience questionnaires would serve as basis for planning and conducting the focus group and mother-father couple interviews (reported in this article) and the concluding questionnaire (reported in Part 2). The plan for assessing how the intervention was experienced by the participants can be outlined as follows.

September 2011

Information was given to health professionals, patients and managements at the Department of Gynecology and the Department of Pediatrics, as well as to the PDC and the academic tutors. Written consent to carry through with the study was given by the two department managements. An ethical application was made. Practical issues were solved. Written information about the study was exhibited to patients (mothers and their next to kin) in the NICU along with information about the improvement project.

October – May 2012

In addition to the intervention process described, experience questionnaires were completed individually by all participants following interviews, feedback sessions, co-design group meeting and follow-up meetings. In January, the father in the family that had been absent twice due to sickness chose to terminate his participation in the study. Following the co-design group meeting on January 18th, one of the staff participants and the mother in the family that had been absent twice due to sickness chose to terminate their participation in the study. They felt they had not entered the improvement work and study in a satisfying way from the beginning. In February, one of the staff members gave birth to a healthy little baby and temporarily resigned her participation.

April – June 2012

On the second follow-up meeting on April 19th, a focus group interview was carried through with participating staff. One staff member was ill, so six out of seven staff members attended the meeting and interview. The focus group interview was conducted by a ward councelor working in the setting and CB. Because (again due to work) only one parent could attend this meeting, it was decided to collect patient experiences by in-depth interviews with each mother-father couple. These interviews with participating mother-father couples were carried through by CB the following week. The analysis of all interviews was completed by CB. The transcripts were copied for the participants so that they could read and validate them, and preliminary results from the analysis were presented and discussed at the third follow-up meeting on May 23rd. Following this, the study results could be summarized for Part 1 and the master thesis was completed. The master thesis was reported according to The SQUIRE (Standards for Quality Improvement Reporting Excellence) guidelines for quality improvement reporting (Ogrinc et al., 2008). Written feedback was also given to study participants.

Methods of evaluation

Mixed, qualitative and quantitative, methods were used to identify and describe the staff and patient experiences in this study. A mixed method approach is described as one in which the study author collects, analyzes and integrates both quantitative and qualitative data in a single study or in multiple studies in a sustained program of inquiry (Creswell, 2003).

- A quantitative analysis of the individual experience questionnaires completed by participants following each event of the improvement intervention.
- Qualitative, evaluative focus group (staff) and in-depth interviews (patients) were held in order to collect and understand the experiences of working together according to Experience-based Co-design (EBCD). Interview questions were partly based on the results from the experience questionnaire analysis.
- A quantitative analysis of a concluding questionnaire following the termination of the improvement process (reported in Part 2). Interview questions were partly based on the results from the evaluative interviews.

The methods of data collection and the analysis are further described below.

Data collection and analysis

The improvement work

Individual interviews with staff and patients were carried out in the initial improvement work by CB. The interviews were analyzed using a summative approach to qualitative content analysis, in order to identify touch points (Bate & Robert, 2007a; Hsieh & Shannon, 2005).

Interviews took place either in the hospital (staff interviews) or in the patients' homes (patient interviews). All patients consisted of mother-father couples. Interviews were tape-recorded and transcribed by a secretary at the local setting and CB. Staff and patient interviews were analyzed separately by CB. Each analysis started with identifying certain words and content in the transcribed text. The text was read several times and words/content was highlighted by hand. The words/content frequency counts were calculated (Hsieh & Shannon, 2005). This quantification was made as an attempt to identify patterns in the data and by this also identifying the so called touch points. The most frequent touch points were derived from the analysis (Bate & Robert, 2007a; Hsieh & Shannon, 2005). Staff touch points were organized into four main areas and patient touch points were organized into three main areas.

After completing the interviews and analyzing the transcripts, feedback sessions were arranged with staff and patients separately. The purpose of the feedback sessions was to validate the findings from the analysis relating to staff and patient experiences respectively, correct or add touch points that may have been missed and agree on touch points to include in the further improvement work. At the feedback sessions each staff and patient participant validated the findings and voted (using five individual votes) for the most important touch points to work further on. Because only one mother-father couple attended the patient feedback session the mother-father couples missing were informed by mail and voted by telephone for the most important touch points. Touch points with the votes are summarized in Table 1 and 2 (see appendices).

A co-design group meeting was held following the two feedback sessions. This meeting represented the first coming together of staff and patients face-to-face. The purpose of the meeting was to share experiences and to identify, agree and define key touch points where improvement work should be made (Bate & Robert, 2007a).

Quantitative, analysis (counting) was made of touch points agreed on at the feedback sessions (reported in this article) and on improvement outcomes (reported in Part 2).

The study of the improvement work

Experience questionnaires were filled in by all participants following each event during the improvement intervention. The questionnaire used was derived from the NHS publication "The experience-based design approach. Experience based design. Using patient and staff experience to design better healthcare services. Guide and tools". The publication was produced as a result of work at the NHS Institute for Innovation and Improvement and contains tools and advice to help putting the EBCD approach into practice. The questionnaire is one of a set of recommended tools to gather people's feelings and emotions of receiving and delivering care (NHS Institute for Innovation and Improvement, 2009). It was translated into Swedish and adjusted to fit the purpose of this study. For example the statement "in pain" was replaced with "uncomfortable". Prefilled statements were happy, involved, safe, good, comfortable, uncomfortable, worried, neglected and sad. Participants were asked to think about how they felt and mark the words (one or more) that best described their feelings at the current event. In addition to estimating the

prefilled statements, participants were encouraged to make comments in their own words. Staff and patients completed identical experience questionnaires. The data was analyzed by descriptive statistics. Prefilled statements frequency were counted and visualized by bar graphs using the Microsoft Excel® analysis tool. The comments by participants in their own words were compiled in a Microsoft Word® format. This method provided a simple approach to capturing feelings and experience.

The qualitative interview method was chosen for its facility to collect, evaluate and understand the experiences of working together according to EBCD. Staff participants were interviewed using a focus group approach. The roots of the focus group interview lie in the methodology of market research and social science. It has become an important research tool in program evaluation, marketing, public policy, health sciences, advertising and communications (Kreuger & Casey, 2009; Stewart, Shamdasani & Rook, 2007). Social science researchers have used focus groups in an explorative way and it has been suggested that focus groups encourage the exploration of feelings rather than the achievement of consensus. They provide a rich and detailed set of data about perceptions, thoughts, feelings and impressions of group members in the members' own words (Millar, Maggs, Warner & Whale, 1996; Stewart et al., 2007).

The focus group interview (staff) took place during the second follow-up meeting and the two in-depth interviews (mother-father couples) took place the following week. Open questions were generated in order to initiate discussion and encourage further exploration (Stewart et al., 2007). The goal was not to build consensus on the issues discussed, but to bring up and capture different views (Kvale & Brinkmann, 2009). The interview questions chosen were partly based on the results from the introductory analysis of the experience questionnaire. Interview questions are displayed in table 3 (see appendices). An interview group generally consists of six to ten people led by a moderator (Chrzanowska, 2002). In this study, staff was interviewed as a focus group and for practical reasons the two mother-father couples were interviewed separately, in their homes. The staff interview group consisted of six people. The moderator of the focus group interview was an experienced ward councelor employed in the local setting and known to the staff. The author of the study (CB) was present during the interview, observing and taking notes to capture the non-verbal data. CB carried out both mother-father couple interviews.

The three interviews were tape-recorded and fully transcribed by CB. In order to increase validity, transcripts were copied for the participants so that they could read and validate what had been recorded. The analysis and interpretation of the data was carried through using qualitative, problem-driven content analysis. Answering the research question using this approach included data making, inferring and narrating (Krippendorff, 2004).

According to Krippendorff (2004), the first step, data making, consists of four components; unitizing, sampling, recording/coding and reducing data. Unitizing is the systematic distinguishing of text that is of interest. Sampling means limiting text to a manageable set of possible units. Recording/coding bridges the gap between unitized texts and someone's reading of them, i.e. the interpretation of the units derived from the text. This is done to create durable, analyzable units of otherwise transient phenomena and transform unedited texts, images or sounds. Reducing data serves the need for efficient, presentable data if data volumes are large and means reducing the diversity of text to what matters. The second step, inferring, moves the analysis outside the data. It bridges the gap between descriptive texts and what they mean, capturing contextual phenomena. The third step, narrating, involves making the results understandable to others by explaining practical significance or contribution of the findings, arguing the appropriateness of the method chosen and making recommendations for actions or further research.

In this study, focus was put on both the manifest content, which deals with the visible, obvious components, and the latent content, which deals with the relationship aspect and involves an interpretation of the underlying meaning of the text (Graneheim & Lundman, 2004). The process started from the research question and proceeded to find analytical paths from choice of text extracts from the transcriptions. What was not said was just as interesting as what was said, which made phenomena not spoken of also important to reveal. The interviews were read through several times to get a sense of wholeness. In the data making process (Krippendorff, 2004) the text about the participants' experiences of EBCD was extracted and brought together into two texts (one for the focus group interview and one for the two mother-father couple interviews) which made the unit of analysis. The texts were divided into textual/meaning units, which is a constellation of words or statements related to each other through their content and context. Textual/meaning units were then reduced/condensed, a process of shortening while still preserving the core. The process whereby the condensed text was abstracted created the codes (for examples, see table 4, appendices). The various codes were compared based on differences and similarities and sorted into eight sub-categories and three categories for staff analysis, and five sub-categories and two categories for patient analysis (for examples, see table 5, appendices) (Graneheim & Lundman, 2004; Krippendorff, 2004). Moving into the latent content, which by Krippendorff (2004) is called inferring, the whole context was considered in an attempt to bridge the gap between the descriptive texts and what they mean and finally, the underlying meaning and the latent content was formulated into two themes (Graneheim & Lundman, 2004). The tentative categories and themes were discussed and approved to by the two academic tutors. Themes, categories and sub-categories constitute the manifest and latent content of the participants' experiences of EBCD in a maternity ward and NICU.

Results

Outcomes

The improvement work

The findings relating to staff and patient experiences (touch points) were rich in data. In the analysis, staff touch points were organized into four main areas. Patient touch points were organized into three main areas. Each staff and patient participant validated the findings and voted for the most important touch points to work further on. Touch points with the votes displayed are summarized in Table 1 and 2 (see appendices).

What are the touch points identified by staff that are not touch points identified by patients?
A total of 26 touch points emerged during the staff touch point analysis (see appendices, table 1). Many common experiences and feelings were expressed from different angles both positively and negatively.

> **Staff touch points** were organized in the following four main areas (with staff voting in brackets):
>
>   1. The maternity ward and NICU collaboration (18 votes)
>   2. A stressful situation for the staff (10 votes)
>   3. A stressful situation for the parents (4 votes)
>   4. Information (4 votes)

The touch points identified by staff but not by patients were mainly the ones concerning **maternity ward and NICU collaboration**. These touch points were also perceived by staff to be the most important issues to work on. Because of this result, the staff who attended the co-design group meeting decided to inform the local collaborating team (described in "local problem") about these touch points and thus suggest further improvement work.

Many experiences described by staff were about patient experiences. Observing and **experiencing the stress patients are exposed to** is a stressful situation in itself. Part of caring about patients is caring about their experiences, and this was therefore a recurrent theme in staff interviews. In contrast, patients did not identify any touch points about staff experiences corresponding to this.

What are the touch points identified by patients, that have not been perceived as touch points by staff?

A total of 21 touch points emerged during the patient touch point analysis (see appendices, table 2). Although every mother-father couple had their own unique story to tell, many common experiences and feelings were expressed in their stories. Experiences were expressed from different angles, positively and negatively.

> **Patient touch points** were organized in the following three main areas (with patient voting in brackets):
>
>   1. Stress (17 votes)
>   2. Information (13 votes)
>   3. The baby (0 votes)

Among the touch points identified by patients but not by staff are the touch points that emerged from **the stories about the baby**. Meeting the baby for the first time is one of the touch points appearing in every patient story. Even so, none of the touch points concerning the baby got any votes as the most important touch points to work further on. Nevertheless, there was a lively discussion about them at the co-design group meeting. Staff noted that having the **celebration coffee at the delivery ward after birth** (which is a common routine at Swedish delivery settings) **without the baby** present can be a bad experience for parents because they miss their baby and want to know how it is doing. This was something staff had not thought of before.

There is a clear need for support from staff, information and time expressed in patient stories. But **experiencing crowds of staff**, for example in emergency situations or at ward rounds, is not always a good experience for the patient. This was a touch point that had not been perceived by staff and was also discussed at the co-design group meeting. When a lot of staff suddenly comes to assistance, it can increase anxiety.

The experiences of **processing and reflecting at home** were strongly put forward in patient stories. Staff was not aware of this being such a big issue for patients. Many care situations are

viewed as routine activities. It can for example concern neonatal jaundice, slight prematurity or hypoglycemia post delivery. Frequent neonatal conditions are often relatively easy to address, so follow-ups are therefore not considered very important. But parents struggle with processing their experiences long after the hospitalization.

What are the touch points identified as areas for improvement by both patients and staff?
The priorities identified and the following discussions were finalized at the co-design group meeting. Patients urged the need for staff support, information and time in many different aspects. The staff also concentrated on information and time issues as areas for improvement, and these touch points were subject to a busy debate. The experiences of processing and reflecting at home were also lively discussed, and finally the two improvement areas emerged as important to all participants.

Two separate co-design teams were formed following the discussion during the initial co-design group meeting;
- The information team
- The follow-up/feedback team

"**The information team**" was entirely consistent with the priorities identified by both staff and patients. "**The follow-up/feedback team**" emerged from the experience-based design process. The opportunities for feedback and debriefing were also stressed in staff interviews, but only in relation to the maternity ward and NICU collaboration and not in relation to patients' needs. The emphasis on the experiences of processing and reflecting at home came very much from patients and the importance of this emerged from discussions at the co-design group meeting itself.

What are the results of the improvement work carried out jointly by patients and staff?
The results are reported in Part 2.

The study of the improvement work
What are the patient and staff experiences of working together according to "Experience-based Co-design"?
The introductory analysis of the experience questionnaires that took place following the co-design group meeting and partly formed the basis of the qualitative interview questions, revealed **most positive experiences** of the improvement work participation so far. Both staff and patient participants stated generally happy, involved, safe, good and comfortable experiences following each event (see figure 4).
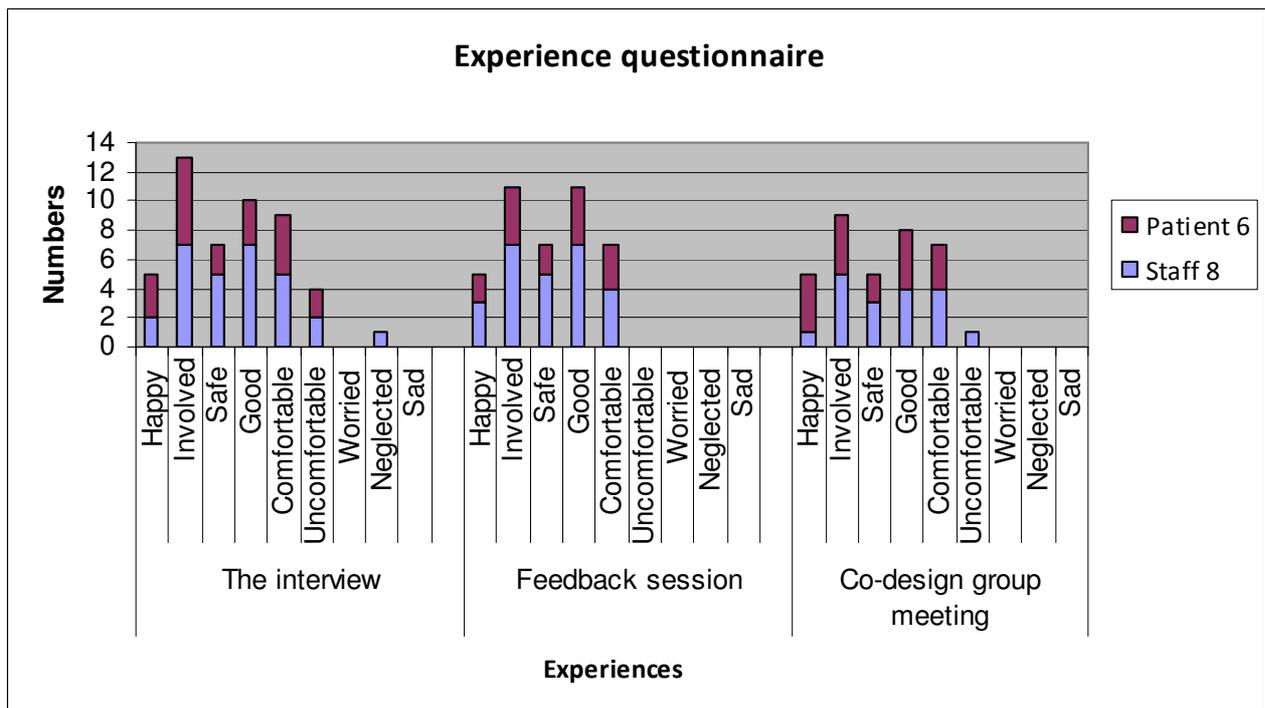
Figure 4: The result of the experience questionnaire analysis prior to the interviews. Both patient and staff statements are displayed.

In addition to estimating the prefilled statements of the experience questionnaires, many comments by participants were made in their own words. According to the written comments, both staff and patients were interested in the chosen area for improvement work (the chosen microsystem) and each other's touch points. They were also expressing excitement about the improvement work to come. One of the staff wrote a comment following the staff feedback session:

"It looks exciting, how will it end?"

One of the parents commented following the co-design meeting:

"It feels like we will start to work now and it will be interesting."

The experiences of the focus group interview (six staff members) and the two in-depth interviews (mother-father couples) were rich in data. As the discussions took place the emotions intensified as participants put words to their experiences. Experiences were continuously angled and developed reflectively. These experiences should influence further planning and implementation of the EBCD process by providing a perspective grounded by their own experience-based understanding of their participation. Two themes emerged during the analysis, one for the focus group interview and one for the in-depth interviews. Themes, categories and sub-categories for the interviews are presented in figure 5 and 6.

Theme	**LEARNING WITHIN THE MICROSYSTEM**		
Category	PRACTICAL ISSUES	MOVING BEYOND ASSUMPTIONS	A NEW WAY OF THINKING
Sub-category	- Time - Organization - Structure, management and planning	- Improvement team progress - Face-to-face meetings - Learning from parents	- A new attitude - Microsystem responsibility

Figure 5: Theme, categories and sub-categories from content analysis of staff focus group interview about experiences of working together according to Experience-based Co-design.

Learning within the microsystem (the overarching theme of the staff focus group interview)

Many experiences expressed by staff addressed the **practical issues** of the improvement project. It could for example concern problems identifying time where everyone in the team was able to attend a meeting, a task complicated by the fact that everyone was working a three shift schedule. The improvement work also proved to involve more work than expected. From the interview analysis it became clear that some participants believed they had understood the EBCD improvement approach, but missed the detail that work in improvement teams was also expected. Staff also experienced a barrier in organizational boundaries, since teams included health professionals from two separate departments. Although maternity ward /NICU collaboration was prioritized and improved cooperation between clinicians for the patients' sake was seen as a critical focus of the project to everyone, differing expectations among staff as to how practical issues were to be solved, disrupted the teams' work. Staff also would have preferred a larger parent group involved in the project. A larger parent group would have brought stronger representativeness, validity and dynamism to the project. Good structure, management and planning were seen as one of the strengths of the improvement project. The long-term planning of various events was appreciated. Continuous information, feedback and support throughout the project created a safe and supportive environment for participants.

"…it is hard to find time, just as you say, when one of us has got time the other one is working and the other way around, it's a hopeless situation…" (Midwife, Department of Gynecology)

"Yes, exactly, it's the structure, it's been a great structure. Good feedback, good support, the information when there has been something. We've known well in advance, this and this is what we're going to do at this point, this is how the approach is going to be. It gives one a sense of security, I think." (Midwife, Department of Gynecology)

Staff also talked about **moving beyond the assumptions** of improvement work. Working in mixed teams, with members from different departments and professions collaborating, was ex-

perienced as stimulating for the individuals and leading to development of the department services as a whole. For some team members, the <u>improvement team progress</u> also included a first introduction to improvement knowledge and the various improvement tools and techniques, and learning about this was also seen as a developing experience. The importance of <u>face-to-face meetings</u> was also stressed. Participants felt that it was during face-to-face meetings that things would evolve. Co-design team meetings and follow-up meetings, with parents and executives participating, were perceived as very important for keeping everyone up to date and for the on-going development of the improvement project. Having parents present at meetings was particularly crucial to the improvement work progress. E-mail and telephone contacts were not always experienced as sufficient. Participants suggested that face-to-face meetings provided opportunities to <u>learn from parents</u>. Many things that were raised by parents were issues that staff had never considered before. Getting information directly from parents and communicating continuously throughout the improvement project was seen as a strong asset which contributed to strengthening the whole process. Participants discussed the feeling that focus had moved beyond the assumptions of improvement work and they felt they were focusing on the correct areas for improvement.

"It's fun to incorporate what parents think into our work. We sit here and believe a lot of stuff, it's not certain that it's all true. So it's much better to have them with you, then you get very different views and other things come up, like you said, things we've never considered." (Midwife, Department of Gynecology)

"Yes, because usually when we work in projects it's what we think… it's our assumptions. It's a big difference." (Children's nurse, Department of Pediatrics)

Participants in the focus interview group identified that being involved in the improvement project had given them a new mindset, **a new way of thinking**. Many experiences were reformulated by adding the context of the parents' way of thinking, to that of the staff, and this had provided them with <u>a new attitude</u> that strengthened their daily work. Staff felt they were more careful with regard to how they dealt with parents and felt more responsive to their needs. Maternity ward/NICU cooperation was also strengthened at a personal level because they believed they had gained a greater understanding of each other's work. New approaches and mindsets of the healthcare system were also reasoned during the interview. Times are changing, there are new thoughts and ideas, patients belong to a new generation with different needs. The theory of the PDSA cycle as a method for continuous learning and action, and how it affects one's attitude was also discussed. To plan, do, study and act in a constant cycle of feedback was an approach considered to provide benefits for the future. The <u>responsibility of the microsystem</u> was considered to depend on everyone's involvement. In addition to members of the microsystem, involvement of managements at the department-, hospital- and municipal level was considered important. Measurements and results should be reported both up and down in the organization hierarchy. Of major interest to many staff members was how the lessons learned and new insights from participation in the project would be passed on to colleagues; this concern focused in part, on how learning within the microsystem could and should be spread more widely, and furthermore, on the consideration that there may be many other healthcare situations that would benefit from the EBCD approach.

"… and they are the ones we respond to now and that's why it's so important to add their way of thinking so that our care will work because, as I said, they have a new way of thinking." (Children's nurse, Department of Gynecology)

"It should be in your mindset, that's just the way you do things." (Children's nurse, Department of Pediatrics)

Theme	EXPERIENCING INVOLVEMENT IN HEALTHCARE	
Category	PARTICIPATION	IMPROVING FOR THE FUTURE
Sub-category	• Feeling important • Practical issues • Desire for more participants	• Sharing our story • Obtaining common understanding with staff

Figure 6: Theme, categories and sub-categories from content analysis of the mother-father couple in-depth interviews about experiences of working together according to Experience-based Co-design.

Experiencing involvement in healthcare (the overarching theme of the two mother-father couple in-depth interviews)

Many of the parents' experiences concerned different aspects of the **participation** in the improvement project. First of all, they felt they had a certain important role as patients throughout the project. The commitment and responsiveness of the staff was clear to them; they felt staff were interested and wanted to understand their perspective; received information from them; and were eager to collaborate on improving the experiences. The improvement project leaders were also perceived to be dedicated, which had relevance for participation. Meeting outside the healthcare context was considered to be an asset for both staff and parents. Face-to-face meetings with staff were much appreciated and considered necessary, and even remote participation via e-mails and phone contacts was experienced effective where other options were not available. The parents expressed a desire to participate to a higher degree than was practical for them. In both families, it was the mother who had primary responsibility for the parents' participation in the project, because a number of practical issues prevented the fathers from having a more active role. Time, working commitments and travelling distance to the hospital where meetings were organized, tended to complicate participation. In order to get a broader view than their own, parents also desired more participants in terms of parents and staff professionals. Despite this, they still believed more participants would generate roughly the same areas for improvement.

"Yes, I also think it has been really exciting and… then later when you were organized to those teams… ah… it feels like the things I say and… has been valued so much. And I feel that staff appreciates it…"
(Mother/Father)

"... sure we believed that yes, now this will take time and, and the distance… … travelling back and forth, but it has worked out well, sort of, by… well, e-mail and phone, and…" (Mother/Father)

Describing their experiences of the participation, they felt that they were involved in **improving for the future**. When they received the improvement project invitation they wanted, in particular, to reciprocate the healthcare experience at the hospital, by helping with whatever they could. For these parents, it was important to share their stories, including positive experiences they had had

and experiences in need of improvement. One of the factors that led to participation was that they considered having children and becoming parents a fundamental part of life. They also said that they had got into a healthcare situation where this was made more difficult for them, and it was important to improve this experience for future parents or for the next time they were attending the services themselves. But improving the already positive experiences they had enjoyed seemed difficult for them to justify or allocate time and commitment to. Another recurring experience of the improvement project was that they felt that they had <u>obtained a common understanding with the staff</u>. Seeing the process from the staff's perspective had given them an overview of their own experiences, and hearing about staff experiences contributed to an increased awareness and a sense of consensus. Parents also felt that they could contribute to giving staff an improved overview. They additionally highlighted that the improvement project provided a way of getting beyond their assumptions about healthcare. However, the most important goal in the project was to agree on common improvement areas and to find the touch points of focus that they were most eager to do further work on. Though parents had an active role in the improvement process, their view was that the professional responsibilities for the improvement work still remained with the health professionals.

"We have our side of it and staff has of course their side. The problem is that we experience it once while the staff experiences it daily… Yes, they're there all the time… that's the difference, then. Yes…" (Mother/Father)

"And I think it's important that staff and patients meet, are able to discuss, because there's a lot you can say straight out but not understanding the content from the staff's side… so it's important… and also I think it's important for staff to meet with patients not in hospital but outside…" (Mother/Father)

"… we could sit down and they really listened to what we had to say, and those posters you made, you wrote down what was important from our point of view and theirs and you could almost see that some things were the same, that we were thinking the same way…" (Mother/Father)

"Because, I mean, we are their job, and they have to listen a little to what, how we perceive things. Because I mean, if you don't say anything they won't know anything, and then they think everything is fine, maybe…"
(Mother/Father)

Discussion

Summary

The improvement work
The findings relating to staff and patient experiences identified many touch points. Staff touch points were organized into four main areas; the maternity ward and NICU collaboration, the stressful situation for staff, the stressful situation for parents and information. Patient touch points were organized into three main areas; stress, information and the baby. Touch points identified by staff but not by patients concerned the maternity ward/NICU collaboration and the experiences of observing the stress patients are exposed to. The touch points identified by patients that had not been perceived as touch points by staff emerged from the stories about the baby, the sudden experience of crowds of staff and the experiences of processing and reflecting at home. At the co-design group meeting, two improvement areas emerged as important to all

participants and two separate co-design teams were formed. "The information team" was entirely consistent with the priorities identified by both staff and patients. "The follow-up/feedback team" emerged from the experience-based co-design process. A few other reflections during the improvement project are also worth mentioning.

- Attracting staff and patients to the improvement project proved to be a difficult and time-consuming task. In addition to this, capturing staff and patients' experiences and identifying touch points through in-depth interviews and qualitative content analysis was also a time-consuming assignment for the improvement leader.

- In order to prepare staff and patients for the improvement work and make them understand their own role, the importance of providing repeated information about the EBCD approach, the improvement project and also feeding back to participants repeatedly was obvious.

- Some staff and patients had more time, energy and commitment than others, which affected the progress of the work in the improvement teams. In addition to this, there was a problem gathering all participants on meetings previously decided upon because of acute illnesses and high workloads.

- The co-design group meeting, which gathered staff and patients for the first time, turned out to be a key point for participants. Sharing touch points, selecting improvement areas and deciding next steps was crucial for the continuation of the improvement project, and participants who did not attend this meeting were likely to withdraw their participation.

The results of the improvement work carried out jointly in co-design teams and from achieving closure of the improvement project are reported in Part 2.

The study of the improvement work

The introductory analysis of the experience questionnaires revealed most positive experiences of the improvement project participation so far. Both staff and patient participants stated generally happy, involved, safe, good and comfortable experiences following each event.

Two themes emerged during the qualitative, problem-driven content analysis. For staff participants the improvement project was a matter of learning within the microsystem through managing practical issues, moving beyond assumptions of improvement work and gaining a new way of thinking. For patients, taking part of the improvement project was expressed as the experience of involvement in healthcare through participation and a sense of improving for the future.

The results from the concluding questionnaire at the termination of the improvement project are reported in Part 2.

Relation to other studies

The improvement work
Engaging staff and patients to the improvement project
Attracting staff and patients to a co-design project can be difficult and time-consuming (Greenalgh et al., 2011), and so it also turned out to be in this case. Staff members of the existing maternity ward/NICU team in the setting, described in "local problem", were initially invited to join the improvement project, but only three of them agreed to participate. The main reason for declining was their belief that participation would add to their overall workload, but there could be other unspoken reasons. Health professional attitudes differ according to individual ideologies, circumstances and needs and because of this patient involvement may be limited (Fudge et al., 2008; Gagliardi et al., 2008). There might be a fear of involving patients, or an underestimation of what patients can contribute to the already existing professional knowledge. There might also be a perception that there is a lack of evidence for this kind of practice (Johnson et al., 2008). Staff participants were therefore mainly recruited from other employees in the maternity ward/NICU. Nevertheless, all participants were truly committed to the assignment.

In the process of recruiting patients, their ability to participate coincided with personal issues as work, childcare commitments and travelling distances. Most parents invited were dedicated to the improvement project idea but regretfully it made no difference since they belong to an active, mid-life target group with a very limited amount of time. These reflections are consistent with previous research (Greenalgh et al., 2011).

Preparing staff and patients for the improvement work
In order to prepare staff and patients for the improvement work and make them understand their own role, the importance of providing repeated information about EBCD, the current improvement project and also feeding back to participants repeatedly was obvious. The EBCD approach was a new approach, and efforts to be clear and forthcoming were therefore welcomed by participants who expressed it as making them feel secure about what was expected of them as the project proceeded. The improvement project was visualized and explained with posters at each event, and current documents were distributed to participants continuously. Greenalgh et al. (2011) also emphasizes the importance of clear information and preparing staff and patients, helping them to develop realistic expectations of what can and can not be achieved. If staff do not understand or value the idea of co-designing with patients they might delay or even block development.

Identifying touch points, selecting improvement areas and deciding next steps
Furthermore, Greenalgh et al. (2011) stress the challenge of identifying problems, selecting improvement areas and deciding next steps. Among other things, they alert the risk that patients may be unconsciously reluctant to identify service shortages in services on which they are dependent, unfamiliar with what is considered as "best practice" and unaware of alternatives available. This was not considered difficult in the present improvement project. The objective of EBCD is about patients and staff experiences playing the major role in the process (Bate & Robert, 2006; Bate & Robert, 2007a; Bate, Mendel & Robert, 2008; Maher & Baxter, 2009), which was also the foundation of this improvement project. The process conditions were as equal as they could be for staff and patients from the beginning. The process of identifying touch points was transparently fed back to participants, staff and patients separately, and they were given the opportunity to correct, add and withdraw from the whole. Selecting improvement areas

was smoothly done as they emerged from discussions at the co-design group meeting, and participants left the meeting with a general agreement in opinion. "The information team" was entirely consistent with the priorities identified by both staff and patients, and "The follow-up/feedback team" emerged from the experience-based design process. The author of the study believes that as a whole, we stayed true to the EBCD core methodology throughout the project.

However, challenges did occur at the point the improvement work in teams began. The co-design teams were coached by CB and the PDC, and during the first months three follow-up meetings were arranged to gather all co-design team members. Surprisingly, since two small departments where people know each other and collaborate daily were involved, it appeared teams needed time to get to know each other. In addition to this they were involved in a new situation with patients to relate to. Teams were occupied working out how to collaborate for some time. According to Bate and Robert (2007a) patients and staff should be allowed space and time to talk about their experiences in the overall process, and moving too quickly to the co-design group stage might result in an unequal partnership. Reflections from this study may be that one co-design meeting is not enough to get the improvement work in teams going. More time with staff and patients invested at the beginning could be well invested time for the project as a whole, and frequent follow-up meetings in the beginning could be valuable. In addition, one of the mother-father couples was not as committed as the other because of work/childcare commitments and travelling distances. They also expressed in general positive experiences, which reduced their motivation to prioritize face-to-face team work.

Making involvement worthwhile for staff and patients
Making involvement achievable and worthwhile is another challenge (Greenalgh et al., 2011). Patients have a positive attitude about being engaged in their healthcare, for example in safety issues, at a general level. But their level of comfort and intensions to act vary (Schwappach, 2010). In this project some staff and patients had more time, energy and commitment than others, which affected the progress of the work in the improvement teams. Patient engagement proved to be a key point for successful progress. One of the mother-father couples was not able to attend all meetings, making face-to-face meetings rare. To the improvement leader it was important to be flexible so staff and patients could choose what they felt willing and able to do, which is also described by Davis et al. (2007), but at the same time push them gently to make progress in the improvement work.

Staff attended the project during working hours, but no payment was given to patients. The only benefits for patients were refreshments and a personal belief of having something to contribute that would actually make a difference. According to Greenalgh et al. (2011) payment can be an important incentive for participation. For instance a substitution of travel expenses would have made involvement easier and more worthwhile for a greater number of parents.

Achieving closure
Reflections from the termination of the improvement project are discussed in Part 2.

The study of the improvement work

Learning within the microsystem (the overarching theme of the staff focus group interview)
Not surprisingly, **practical issues** colour staff experiences much and these issues become a big obstacle to all attempts of planning the work in improvement teams. In general, staff in the healthcare sector always seems to be in a lack of time, making quality improvement only prioritized when there is a little time to spare. In addition to this, working in delivery and maternity

wards, and in NICU settings, is emergency care with working conditions shifting by the hour. Adding the fact that staff participants were working a three shift schedule made attempts to plan even more complex. At the start of the interview, these issues were lively addressed. There was also an invisible barrier in the organization because team members were working in two different departments. Though not spoken of, the boundaries were there, initially influencing the improvement work in teams. But despite all the practical and organizational restraints, creating a safe, supportive and well-informed environment in the project contributed to good experiences of the improvement work for staff (Greenalgh et al., 2011). Creating this environment is one of the main tasks for the improvement leader.

In line with the results of the case study of using an EBCD approach in a pilot study in England (Bate & Robert, 2007a), staff participants in this study confirmed that the patient participation throughout the project had been a key feature. Staff expressed the strong asset of continuous and direct communication with patients, making them feel they had **moved beyond their assumptions** about the patients' views and improvement work. They were convinced they were working on the correct improvements using the EBCD approach. Consistent with Greenalgh et al. (2011), staff expressed that patient experiences and stories can be invaluable teaching material, and that they were learning from patients. Patient experiences were not seen as a rival to other evidence base, but as an important complement to the whole picture. As many scientists claim, learning is a social action and interaction is essential to be able to learn (Argyris & Schön, 1978). Staff expressed the necessity of face-to-face meetings with patients, experiencing that during these meetings important things would evolve. The institute for Family Centered Care and the Institute for Health Care Improvement have developed a report on patient-centred care (Johnson et al., 2008). The report highlights, among other things, that patients and families at a microsystem level should participate as full members of quality improvement and redesign teams, participating from the beginning in planning, implementing and evaluating change. The EBCD approach gives patients and staff the opportunity to accomplish this, which was noticed and highly appreciated by participating staff in this study.

Moreover, being involved in this improvement project had given staff a new mindset, a **new way of thinking**. By adding patients' experiences, developing shared meanings and creating collective sense-making with patients (Bate & Robert, 2007a) they believed they had gained a new attitude in their daily work. Some of their new knowledge was considered explicit, other tacit. While explicit knowledge is possible to store in a mechanical, technological or electronic way, for example the amount and variety of touch points and improvement outcomes, tacit knowledge is mostly stored only in human beings. This kind of knowledge is obtained by internal individual processes like experience and reflection, and can therefore not be managed and taught in the same manner as explicit knowledge. Approaches that encourage direct interaction, networking and action learning that include face-to-face social interaction and practical experiences are more suitable for the sharing of tacit knowledge (Haldin-Herrgard, 2000). By staff participants, the tacit knowledge gained was on one hand considered in terms of the way it strengthened themselves in relation to patients and to each other. But on the other hand difficulties in managing and sharing the new knowledge to colleagues were frequently reflected upon. Bate and Robert (2007a) emphasizes the process of ongoing evaluation for learning, and this continuous cycle was also pointed out by staff as contributing to their new way of thinking. Related to this was the theory of the PDSA cycle as a method for continuous learning and action (Langley et al., 2009) that also was perceived giving new insights. In line with what Nelson et al. (2007) describes, staff meant that a successful redesign requires creating proper conditions for learning, improvement and accountability at all levels of the organization. And as they furthermore reasoned, measurements and results must be reported both up and down the organization hierarchy making the responsibility for the development of the microsystem depend on accountability at all organizational levels.

Experiencing involvement in healthcare (the overarching theme of the two mother-father couple in-depth interviews)

The various aspects of **participation** in the improvement project were of great concern to the parents. First of all, staff seemed to play an important role in engaging them and keeping them engaged throughout the improvement project. As Schwappach (2010) suggests, the involvement of patients (in safety) may be successful if, among other things, initiatives are based on their perspectives. Parents in this study also clearly argued the great importance that they are placed at the centre of healthcare, although focus in this study was kept on experiences and not safety. The commitment and responsiveness of the staff and the improvement project leaders made them feel valuable which added relevance for participating. Second, and in line with staff views, parents also requested more parent and staff professional participants. They felt they needed a broader view which more parents and staff professionals would have been able to provide. Third, practical issues were significant. These issues prevented families living at a distance from the hospital, where meetings were held, to prioritize the improvement work. Additionally, the fathers were not able to be equally and actively involved because of work commitments. In conclusion, patients who recently have become parents are very dedicated to improving healthcare, but practical issues complicate their participation.

Patients want to share their story and they want to be involved in their healthcare. They want to know when things go right and be part of the solution when things go wrong. Several studies describe patients' experiences of healthcare of which participation in a NICU context is of particular focus here (Reis et al., 2009; Fegran et al., 2006; Greisen et al., 2009; Yee & Ross, 2006). Patients also want their care to be designed around them (Bate & Robert, 2007a). Parents participating in this study felt that by sharing their story, they were **improving for the future**. By participating in this improvement project they were contributing to improved healthcare for other patients and for themselves in future healthcare situations. Bate and Robert (2007a) also emphasizes the strong relationship that occurs between patients and staff to be one of the keys to success. This sense of community was also remarked upon consistently during staff and parent interviews in this study. Parents felt that they had obtained a common understanding with staff, and that this understanding had contributed to their own experiences. The Johnson et al. (2008) report outlines four concepts that include respect and dignity, information sharing, participation and collaboration. As mentioned earlier, additional recommendations in the report include making partnerships with patients and families an essential aspect of healthcare redesign and quality improvement. This study confirms that, at the experience level, healthcare should be provided respectfully, assuring a sincere sharing of useful information within the microsystem continuously, supporting and encouraging the equal participation of patients and staff. Parents can contribute to the EBCD process of gathering information about their experiences, analyzing and responding to collected data, and engaging themselves in improving the same. Furthermore, Schwappach (2010) suggests that the involvement of patients may be successful if their implementation is based on serious efforts for cultural change in healthcare settings. This was also argued by parent participants in this study. They were eager that the improvement work they were putting effort in should yield future results. Patient responsibility for the improvement work was perceived as one of the central characteristics of the EBCD approach in the Bate and Robert (2007a) study. Their reflections were that the process had given patients a greater sense of responsibility for the work and its outcomes. This was not so obvious in this study. Parents were willing to contribute to future care, but as Davis et al. (2007) also reason, despite their participation and commitment the responsibility of the improvement work was seen as mainly the responsibility of the healthcare professionals.

Limitations

The improvement work

Some limitations of the improvement work so far have to be taken into consideration. Obviously, the involvement of more patient and staff professionals would have broadened the process of identifying touch points and selecting improvement areas, which would have added more value and learning to the improvement project as a whole.

In addition to being few participants involved, there was a problem gathering all participants on meetings decided upon because of acute illnesses, high workloads and travelling distances. There was never a meeting with all participants present, which may have affected the improvement project negatively. Results from the interview analysis support the importance of face-to-face meetings to keep everyone up to date with the process.

Though there was a clear strive for equal partnership between staff and patients in the improvement project, it was not fully accomplished. Fathers were not able to engage themselves in a way they wished to due to working commitments. Staff attended the meetings during working hours whilst no payment was given to patients. Payment, for instance substitution for travel expenses and loss of earnings, could be an important incentive for participation and would have made involvement easier and more worthwhile for parents.

The study of the improvement work

The study of the improvement work has some limitations that need to be considered. First, the questionnaire used was derived from the NHS publication "The experience-based design approach. Experience based design. Using patient and staff experience to design better healthcare services. Guide and tools". The publication was produced as a result of work at the NHS Institute for Innovation and Improvement and contains tools and advice to help putting the EBCD approach into practice. The experience questionnaire is one of a set of recommended tools to gather peoples' feelings and emotions of receiving and delivering care (NHS Institute for Innovation and Improvement, 2009). Generally, administering questionnaires in order to obtain complete and accurate data is a sophisticated task which if not done to a very high standard will result in poor quality data from which few conclusions can be drawn. No work on the validity and reliability of this experience questionnaire has been done. When discussing it NHS Institute for Innovation and Improvement question if it would be a useful thing to do. Although it is termed a "questionnaire", in reality it is a structured way if capturing experience, different from a normal questionnaire design. According to Mark Mugglestone, Head of Innovation, NHS Institute for Innovation and Improvement, emphasize is made on the involvement of both patients and staff members throughout the EBCD process, and this involvement helps to ensure some element of validity (M. Mugglestone, personal communication, May 11th, 2012). In this study, the experience questionnaire was used as a simple approach to capturing feelings and experience, preparing for the formulation of the interview questions. Results from the initial analysis were fed back to participants, which can be regarded as a form of validation.

Second, the author had the initial analysis of the experience questionnaires to ground the interview questions on, but as they revealed most positive experiences, a set of evaluative questions were also added (see table 3, appendices). The design of the interview questions is also a critical task because it establishes the agenda for the group discussion and provides a structure within

which participants may interact and articulate their thoughts and feelings (Stewart et al., 2007). The types of questions chosen originated from the summative evaluation of the Bate and Robert (2007a) study and were approved to by the two academic tutors.

Third, most regretfully and due to practical reasons, the initial evaluation plan had to be revised and the two mother-father couples were interviewed in their homes respectively. In this study, the focus group method was seen as a useful way of pursuing the aim of effectively ascertaining staff and patient experiences. It was seen as a source of very rich, meaningful data that moved beyond normative perspectives to capture real experience. The staff focus group consisted of six members, and everyone knew one another. The group discussed at length many sensitive issues. Because the two mother-father couples could not be interviewed together, the positive group dynamics and interaction that enhance data collection might not have been accomplished although interview questions were identical.

Finally, the questions of reliability, validity and generalizability for this study must be discussed. For qualitative studies, the criteria of Lincoln and Guba (1985) related to trustworthiness are often used (Polit & Beck, 2008). Four criteria regarding the trustworthiness of qualitative studies are described in the literature; credibility in data collection and analysis, transferability of results to other contexts, dependability regardless of the researcher's perspective, and confirmability, the ability for someone other than the researcher to confirm the results (Lincoln & Guba, 1985). One way to enhance trustworthiness is to use the most appropriate data collection method and describe in detail how the analysis was carried out. Trustworthiness also depends on the reliability of the analysis process. In this study, because few patients participated in the improvement project, few respondents were interviewed, and circumstances during the interview sessions were not identical for staff and patient participants. Despite this, the author of the study believes the qualitative approach still provided a suitable platform for participants to tell their stories and provide useful information about their experiences of the improvement project, in line with the aim of the study. The use of interviews provided a valuable opportunity to explore thoughts and feelings of respondents in more depth than would have been otherwise feasible. Nevertheless, it is evident that more patient and staff professional participants would have broadened the results. Results and interpretations have been transparently fed back in an ongoing process between the author of the study, the two academic tutors and the participants of the study. The author of the study believes these different perspectives and experiences have helped to strengthen the credibility of the findings (Lincoln & Guba, 1985; Polit & Beck, 2008). Furthermore, in qualitative methods the criteria of transferability of results to contexts other than where the study was completed is discussed. A clear description of both the participants and the context in which the study was conducted is necessary for readers to assess the validity of the results basis on transferability to other contexts (Polit & Beck, 2008). Transferability of results to other contexts was not the main purpose of this study. The author was interested in learning from the experiences expressed of this particular improvement project, in order to improve future EBCD processes in the same or other contexts. This approach is related to the theory of the PDSA cycle as a model for learning and action (Langley et al., 2009). The author was equipped with much pre-understanding, which may have affected the dependability of the study and can not be ignored. First, the author of the study possessed the full background knowledge about the services and context studied from working in the setting and previous research. In addition, the author was a master student at the Master's Program of Quality Improvement and Leadership in Health and Welfare Services, which may have affected the interpretation in the analysis. The ability for others than the author of the study to confirm the results, the confirmability, is strengthened by the results described being clarified with quotes. The participants' own words illustrate that results are grounded on their own descriptions rather than by the author of the study's perspective and pre-understanding (Polit & Beck, 2008).

Conclusions

This study confirmed that, despite practical obstacles for participants, the EBCD approach to improvement work provided an opportunity for maternity ward /NICU care being explored respectfully at the experience level, by assuring the sincere sharing of useful information within the microsystem continuously, and by encouraging and supporting the equal involvement of both staff and patients. Staff and patients wanted and were able to contribute to the EBCD process of gathering information about their experiences, analyzing and responding to collected data, and engaging themselves in improving the same. Furthermore, the EBCD approach provided staff and patients the opportunity of learning within the microsystem. Nevertheless, the responsibility of the improvement work remained the responsibility of the healthcare professionals.

It is the author's opinion that future healthcare research should continue focusing on experience-based approaches to quality improvement, involving staff and patients on equal basis, but without handing over the responsibility on patients. This improvement project and study of the improvement project raised several further questions. What other patient populations and staff professionals could also find the EBCD approach valuable? How can we recruit staff and patients to a co-design project in a less time-consuming way? How can we manage the different practical issues of participation better? How can we make the process of identifying touch points more efficient without losing important co-design process value? How do we make involvement the most achievable and worthwhile for participants? What are the contents of microsystem learning, how do they develop and in what way can they contribute to healthcare? To the author's knowledge, there is little evidence of what is the most appropriate research design for studying microsystem development and learning, and this should be further explored.

Other information

"You won't find faith or hope down a telescope
You won't find heart and soul in the stars
You can break everything down to chemicals
But you can't explain a love like ours
It's the way we feel
This is real"

Science and Faith – The Script

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Appendices

Table 1.Staff touch points with the result of the voting displayed

A stressful situation for the staff

- Sympathizing with the parents (1)
- Getting the coordination of the family functioning (1)
- Information difficulties
- The emergency situation (2)
- The feeling of a bad experience for the parents even though you think you made the best possible out of the situation
- Time constraints (2)
- When you experience the involvement of parents (3)
- Being professional (1)

A stressful situation for the parents

- The trauma for the family
- The ignorance of the parents
- Information difficulties (2)
- When the parents become invisible
- The parents' ambivalence
- The feeling of being able to support the parents (2)
- The experience of having a good relation to the parents

Information

- The situation when direct information is not possible to achieve
- The experience of parents not getting the right information at the right time from the right health profession
- Well-informed parents
- When the teamwork concerning patient information functions (4)

The maternity ward and NICU collaboration

- When communication is unclear/ The perception that communication works (3)
- When staff feel they do not understand each other (3)
- The opportunities for feedback and debriefing (3)
- The perception of parents becoming invisible (3)
- When the practical cooperation does not work/ When it does work (4)
- When one does not agree
- The experience of the first meeting with the family (2)

Table 2.Patient touch points with the result of the voting displayed

Stress

- Trying to understand what is happening and what the consequences are
- Reliance on staff (5)
- Pendulating between peace and chaos (1)
- The support from staff (5)
- Informing the family and holding it together
- The need for time with staff (4)
- NICU (1)
- Being responsible for the baby at the maternity ward and in the NICU
- Too many staff
- Processing and reflecting at home (1)

Information

- The ambiguity, embellishment and the dual information (6)
- The experience of not getting the right information at the right time from the right health profession (3)
- Confirmation and feedback (2)
- Continuity
- Written/verbal (2)
- The information folder

The baby

- The obvious need to be near the baby
- The experience of the first meeting with the baby
- The medical treatment
- Having the celebration coffee at the delivery ward without the baby present
- Time

Table 3.Interview questions – focus group/mother-father couple interviews (staff and patients)

INFORMATION:
- Information about the study of the improvement project
- Gaining informed consent
- Information about the focus group interview approach:
  - Participants should primarily discuss the questions given as a conversation
  - Participants should all be given the same amount of time and space during the interview
  - Estimated time needed is about one hour
- The author of the study presents her role during the interview; observing, taking notes and perhaps asking a few questions

INTERVIEW:
Tell us your story about the involvement in this project! We are interested in knowing what your experiences are.
- What did you experience when being asked to participate?
- Why did you agree to participate?
- How would you describe what you and the other participants have been doing to others who do not know anything about it?
- What has it felt like to be involved?
- How have you experienced working with parents/staff?

(STAFF ONLY:
- How has this project of improvement work differed from others you have been involved with? Why?)

- What have been the most important parts of the project? Why?
- Tell us about something that worked well in the project.
- Tell us about something that did not work so well or has been a disappointment in the project. How can a project like this be improved?
- What improvements do you think this project could lead to? Will it be long lasting benefits?
- Would you recommend this as something for other staff/parents/patients to get involved with? Why?
- Are there other ways to work with this?
- What do you think will happen now? Will the work continue, and if so, in what form?
- Is there anything else you would like to add before we end the interview?

THANK YOU TO PARTICIPANTS

Table 4.Examples of meaning units, condensed meaning units and codes.

Meaning unit	Condensed meaning unit	Code
… and also we are two different wards, so it's difficult getting it together sometimes…	two different wards difficult getting it together	two wards and departments
... coming with our, I mean point of view, or our story, the way we experienced it…	coming with our story and experience	telling our story

Table 5.Examples of codes, sub-categories and categories.

Category	PRACTICAL ISSUES			IMPROVING FOR THE FUTURE	
Sub-category	Time	Organization	Structure, management, planning	Sharing our story	Obtaining common understanding with staff
Codes	time constraints locating time	two wards and departments collaboration participants	leadership information feedback support long-term planning	telling our story helping improving positive experiences hard to motivate	take part of staff views holistic view moving beyond assumptions finding joint improvements responsibility for improvements