Indian nurses’ experiences of supporting parents of children with cleft lip and palate
A MINOR FIELD STUDY

Julia Hjalmarsson
Karin Kjernald
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Authors: Julia Hjalmarsson, Karin Kjernald

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Supervisor: Kristina Nässén

Examiner: Elisabeth Jangsten

Abstract

The aim of this study was to describe the nurses’ experiences of supporting parents whose children are subjects of the Nutrition Program at Guwahati Comprehensive Cleft Care Center. Cleft lip and palate are congenital malformations of the face, where nose, lip and/or upper jaw fail to coalesce adequately in utero, creating a gap. The organization Operation Smile provides free reconstructive surgery to children with facial malformations. The Guwahati Comprehensive Cleft Care Center in Assam was founded with the knowledge that the population in this area is largely underserved in relation to the care of these patients. Children with clefts are commonly malnourished; children who suffer from moderate or severe malnutrition are prone to infectious complications associated with surgical procedures. To enhance patient safety and improve the chances of successful interventions, the Operation Smile India Nutrition Program was started in 2011. The parents of children who are enrolled in the Nutrition Program get education by trained nurses. The education contains thorough information on how children can best assimilate nutrition and how their diet should be designed at different ages. There is a lack of studies about the nurse’s experiences of supporting the parents on this matter. It is of great interest to examine nurses’ experiences of supporting the parents of children with cleft lip or palate. The study was based on a qualitative approach, and semi-structured interviews were conducted with six nurses. The interviews were transcribed and the material was analyzed with qualitative content analysis. Three categories were discerned in the transcribed material: Caring actions, Education and Creating trust. Each category is followed by a number of subcategories. The findings show that the relationship to the parents was crucial for the nurses’ supporting actions to succeed. In the discussion, certain aspects of the findings are highlighted, such as the nurses’ emotional involvement and their way of admonishing the parents. Some aspects of the nurses’ work with supporting the parents are applicable to nurses’ work with next of kin anywhere in the world.

Keywords: Cleft lip, cleft palate, nurse, parents, support, malnutrition
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INTRODUCTION

India is a country with more than one billion inhabitants and twenty-two official languages and numerous dialects. Among the great population there are large spans of living conditions. A significant part of the children who are born into poor living conditions sometimes don’t get the same possibilities in life in sectors such as health care and education, as children born into more affluent living conditions; because of this Operation Smile was founded.

Through cooperation between Indian health care professionals and international volunteers working for the international organization Operation Smile, children with congenital malformations of the face are offered free reconstructive surgery and thereby a chance for a better future. When the authors became aware of the life-changing procedures that children with congenital malformations obtain through the work of Operation Smile and heard that the nurses within the organization were driven by a deep desire to do good for other people, the idea of performing this study¹ was born. On a daily basis, children with cleft lip or palate get free reconstructive surgery at Guwahati Comprehensive Cleft Care Center. The nurses at the center care for the children both pre-, peri- and postoperatively. Through supporting the parents preoperatively, the nurses play a crucial part in helping the children who are going through this life changing process.

BACKGROUND

Convention on the Rights of the Child

Convention on the Rights of the Child (CRC) has been constructed by United Nations and contains provisions on human rights for children. UNICEF is an organ of United Nations and is in charge of CRC. UNICEF do their utmost to ensure that children’s rights must be respected around the world. CRC consists of articles that contains such as: All children have equal rights and equal value, no one shall be discriminated against, all children with disabilities have the right to a full and decent life that enables participation in the society and every child has the right to enjoyment of the highest attainable standard of health and to health care (UNICEF Sweden, 2009).

The nursing profession in India

Though nurses represent the largest health workforce group in India (Gill 2011, p. 54), there is still a shortage of nurses in relation to the services that is needed (WHO 2011). Most of the nurses prefer to work in cities rather than in rural areas, which leads to a problem because there is more request of care in the rural areas. In villages there are women who provide health care without formal education, to compensate for the lack of nurses (Tiwari, Sharma & Zodpey 2012, pp. 130-133).

¹ The authors would like to thank SIDA (Swedish International Development Cooperation Agency) for giving the opportunity to travel to India to perform this minor field study (MFS).
The nursing education in India has grown since India became independent in 1947 and today the nursing requires extensive knowledge and skill. The nursing education tries to achieve a high standard and strives to provide teaching the students to become highly educated. There are still many challenges regarding the nursing education in India. One problem is that the universities have non-uniform syllabi (Tiwari, Sharma & Zodpey 2012, pp. 130-133).

The Indian Nursing Council (INC) is an association that works under the government of India and regulates the profession of nursing in India, both education and work (INC 2014). INC was founded by the Indian Government in 1947 and is affiliated to the International Council of Nurses (ICN). INC strives to create a uniform standard of nursing education, which includes stipulating syllabi for the nursing programs (INC 2014). INC has chosen to adopt the ethical guidelines provided by ICN that states that every nurse should promote health, prevent illness, restore health and ease suffering. The ethical guidelines should therefore be implemented by all nurse professionals in India (ICN 2014).

Prevalence of cleft palate in the state of Assam

India is known to have a high incidence of cleft lip and palate; the birth prevalence of children with these facial malformations is between 27,000 and 33,000 per year (Mossey & Little 2009, p. 9) Assam is a state in the north-east corner of India, with approximately 31 million inhabitants. In Assam, approximately 800-1000 children are born each year with a correctable facial malformation such as a cleft (Operation Smile India 2013).

Cleft lip and palate are congenital malformations of the face, where nose, lip and/or upper jaw fail to coalesce adequately in utero, creating a gap (Gopinath & Wan Muda 2005, p. 254). In the world, clefts have a frequency of one in 700 of human births, making this the most common congenital malformation in the world. Asian and Amerindian countries are known to have the highest frequency (Murray 2002, p. 248). The etiology of these conditions is yet unknown; however there is a consensus that they are due to a combination of genetic and environmental factors (Murray 2002, pp. 252-253; Gopinath & Wan Muda 2005, p. 254). Furthermore, theories say that the abnormalities may be related to the use of drugs such as anticonvulsants during pregnancy and that the risk can be reduced if women avoid exposing themselves to drugs, cigarettes and alcohol during pregnancy, and use nutritional supplements in the form of folic acid, pyridoxine and other micronutrients (Murray 2002, pp. 252-253). According to Dr. Choudhury many parents, however, believe that the malformations are a punishment from God. Weatherley-White, Eiserman, Beddoe and Vanderberg (2005, p. 562) also found that many Indian parents believed that their child’s cleft was either God’s will or a punishment for something they did wrong.

Without reconstructive surgery, the affected children suffer from great social, functional and psychological disabilities. The functional disabilities include difficulties of

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2 Dhruba Choudhury, M.D., Guwahati Comprehensive Cleft Care Center, personal communication 7th March 2014.
developing speech and ability to feed adequately (Järhult & Offenbartl 2010, pp. 565-566). Children with cleft lip and palate have difficulties with breastfeeding. Despite adequate sucking movements, they lack ability to create a negative pressure during breastfeeding, making the feeding tiresome and difficult. These children swallow more air than what is normal, and often lack energy to complete the feeding session. Due to this, children with clefts often suffer from malnutrition (Gopinath & Wan Muda 2005, p. 254; Järhult & Offenbartl 2010, p. 565). Studies show that these children are compromised in both length, weight and head circumference (Marques, Nackashi, Borgo, Martinelli, Pegoraro-Krook, Williams, Dutka, Seagle, Souza, Garla, Neto, Silva, Graciano, Moorhead, Piazentin-Penna, Feniman, Zimmermann, Bento-Goncalves, Pimentel, Boggis, Jorge, Antonelli & Shuster 2009, pp. 605-607; Gopinath & Wan Muda 2005, p. 254).

**Nutrition Program - a part of Operation Smile**

Operation Smile was founded in 1982 with the vision that no child should be insulted or forced to hide due to a treatable malformation of the face. Thanks to medical volunteers and employees, sharing their time and knowledge, children with cleft palate are offered free reconstructive surgery. Since the start, 200 000 operations have been performed world-wide; however, many children are still in the need of help. During the medical procedures, local medical staff is always participating and the process is always carried out in cooperation with the local health care organization. Another idea of Operation Smile is to educate local medical staff and, with financial support, build independent clinics (Operation Smile International 2013). The Guwahati Comprehensive Cleft Care Center in Assam was founded with the knowledge that the population in this area is largely underserved in relation to the care of these patients; there is a great backlog of children with untreated clefts (Guwahati Comprehensive Cleft Care Center 2011).

Children who suffer from moderate or severe malnutrition are more prone to infectious complications associated with surgical procedures than well-nourished children. In addition, they require longer post-operative hospital stays (Secker & Jeejeebhoy 2007, pp. 1085-1087). To enhance patient safety and improve the chances of successful interventions, the Operation Smile India Nutrition Program was started in 2011 (Guwahati Comprehensive Cleft Care Center 2011).

The Nutrition Program involves all children who are being considered for surgery; the children are examined by anthropometric measurements to identify those who are malnourished. Children deemed in need of urgent medical care because of their bad condition, is put directly onto a ward and others may return home. The parents then get education by trained nurses. The education contains thorough information on how children can best assimilate nutrition and how their diet should be designed at different ages. They also receive information about personal- and food hygiene. Follow-up anthropometric measurements are collected on a regular basis, using the World Health Organizations (WHO) classification of malnutrition. This classification is based on weight for height, height for age, presence of edema and weight for age. When a child’s growth is on the normal curve, he or she is considered to be ready for surgery (Guwahati Comprehensive Cleft Care Center 2011).
Feeding a child with cleft lip or palate

Children with clefts are rarely breastfed; there are however several other possibilities for parents to feed their child. They can be fed expressed breast milk or infant formula by bottle, small cup, syringe, naso- or orogastric tube or with a dropper (Garcez & Giugliani 2005, pp. 689-690). Syringe-fed cleft palate children presented weight gain equivalent to that of non-cleft breast-fed children (Ize-Iyamu & Saheeb 2011 pp. 917-919). In bottle-feeding cleft palate children, it has been suggested that the type-P teat, which is longer and wider than the standard teat, improves feeding efficacy compared to a regular teat (Mizuno, Ueda, Kani & Kawamura 2002, pp. 1229-1231). A palatal obturator can be used to cover the internal cleft in children with cleft palate, making it possible for the child to obtain a negative pressure in the mouth while breast feeding, and to breast feed without occurrence of nasal regurgitation. Cleft palate children who were breastfed with a palatal obturator gained weight equivalently to non-cleft children (Turner, Jacobsen, Humenczuk, Singhai, Moore & Bell 2001, pp. 522-524).

Parents’ experiences

Swedish mothers of babies with cleft lip and palate reported inadequate support from health care professionals regarding the feeding of their children; these mothers worried a lot about the possibly unmet nutritional needs of their children (Lindberg & Berglund 2013, pp. 69-70). Parents in another Swedish study reported that nurses, even though being perceived as kind and helpful, lacked knowledge of how to best feed a child with cleft- or lip palate (Johanson & Ringsberg 2004, pp. 168-169). Parents in a British study, however, were pleased with the support they received on how to best ensure that the child’s nutritional needs were met, even though they still worried a lot about the feeding process (McCorkell, McCarron, Blair & Coates 2012, p. 26). In a study of Thai parents, the parents asked the nurse questions such as how to feed the child and how to eventually choose supplementary foods (Chuacharoen, Ritthagol, Hunsrisakhun & Nilmanat 2009 pp. 254-256). In a study of Indian parents, the majority of the parents expressed worries about the child’s future. They were hoping that the child, if the cleft was repaired, would have better opportunities in life areas such as marriage and education (Weatherley-White, Eiserman, Beddoe & Vanderberg 2005, p. 562).

The caring encounter

The care of any patient should be based on a caritative perspective, meaning that the caring process is characterized by interpersonal love and compassion. The caritative perspective is the ultimate motive to give care to another human (Wiklund 2003, p. 31). The caring encounter is an essential condition for the caring process to take place. Without the caring encounter there is a great risk that the caring will be reduced to a technological or task oriented level. Within the caring encounter, the patient can receive support regarding all various dimensions of the human being, bodily as well as mentally or spiritually. If the caring tends to be exclusively technological or task oriented, the result of the treatment will only be curing of disease and symptoms. When establishing a caring encounter to the patient, the possibilities for teaching and learning are optimized (Wiklund 2003, p. 155). The caring science starting point is that care should be patient-focused, meaning that the care will be executed from the patient's perspective (Dahlberg & Segesten 2010, pp. 118-119). Dahlberg and Segesten (2010, p. 119) says
that patient-focused care also includes the family's perspective; often, a family perspective may be warranted.

PROBLEM STATEMENT

Several studies describe the problems of living with cleft lip and palate. It is well known that children with clefts suffer from severe problems with malnutrition (Gopinath & Wan Muda 2005, p. 254; Järhult & Offenbartl 2010, p. 565; Marques et al 2009, pp. 605-607). It is also known that there is a great educational demand among the parents of these children. At present time there are several studies available that describe parents’ needs and wishes about education and support regarding the nutrition and feeding of their child with cleft lip or palate. As in many other contexts, the nurse is the health care professional closest to the patient (the child) and its next of kin (the parents). Because of this, the nurse plays an important role in supporting the parents on how to best feed the child to meet its nutritional needs. However, there is a lack of studies about the nurse’s experiences of how to support the parents on this matter. Furthermore, no previous nursing research has yet been done at Guwahati Comprehensive Cleft Care Center. An improved understanding of how the nurse experiences her role in supporting the parents might be of use in developing supportive actions in the future. Therefore, it is of great interest to examine the nurses’ experiences of supporting the parents of children with cleft lip or palate within the Nutrition Program at Guwahati Comprehensive Cleft Care Center.

AIM

The aim of this project was to describe the nurses’ experiences of supporting parents whose children are subjects of the Nutrition Program at Guwahati Comprehensive Cleft Care Center.

METHOD

Approach
This study was based on a qualitative approach, as described by Rosberg (2012, pp. 112-115). Qualitative research interviews were performed with a number of nurses. The aim was that the interviewees should get in touch with their experiences and describe them in words. According to Kvale and Brinkmann (2009, p. 43), a qualitative approach means that the researcher tries to understand and emphasize the holistic, complex and subjective aspects of a topic, in this study the nurses’ experiences. The aim within qualitative research is to describe qualitative knowledge expressed in colloquial prose, rather than quantifying it (Kvale & Brinkmann 2009, p. 43; Axelsson 2012, p. 214; Polit & Beck 2010, pp. 17-18).
Participants and settings

One inclusion criterion was that the informants had to be English speaking nurses, involved with Nutrition Program at Guwahati Comprehensive Cleft Care Center. The nursing staff at Guwahati Comprehensive Cleft Care Center consists of nurses whose background and nursing education is European and American, and nurses whose education is Indian. To avoid potential cultural clashes from the international nurses, another inclusion criterion was that the nurses had carried out their nursing education in India. Six nurses with a three-year professional degree in nursing were included. One of them was working on her bachelor's degree. All of the included nurses were born in India but were from different states. They all spoke English and Hindi but not all of them spoke the local language of Assam, Assamese. All of them were women, 20-30 years old and had worked at Guwahati Comprehensive Cleft Care Center for one to four years. All of the nurses met with and supported parents at the Center. The interviews were conducted at Guwahati Comprehensive Cleft Care Center. Four of them were conducted in a secluded cubicle in the ward, one in the doctors’ lounge and one in the reception area.

Ethical considerations

In Sweden, bachelor students are not bound to obtain ethical approval when conducting a research project. Good research practice, in accordance with guidelines of the Swedish Research Council (Vetenskapsrådet 2011, pp. 65-69), was applied throughout the project. Furthermore, the study was given ethical approval by Operation Smile India Institutional Ethics Committee (OSI IEC). An informational letter (see appendix 1), was provided to each of the informants before the interview. The authors verbally explained the content of the informational letter. Time was given for the nurses to ask questions to the authors if anything in the informational letter was unclear. The informational letter contained information about the aim of the study, the anonymity of the participants and their right to withdraw at any time, without further explanation. It also said that the material would be treated confidentially, meaning that it will be read by the authors only and that no one else will be able to access the material. Written consent was obtained from all participants.

Data collection

In the qualitative research interview, the interviewer strives to interact with the respondent to co-create an authentic story (Nunkoosing 2005, p. 701). The authors conducted individual qualitative research interviews in a semi-structured way. A number of prepared, broad questions were asked, leaving the respondents free to talk about their experiences of supporting the parents (interview guide, see appendix 2). When needed, clarifying questions were asked. When conducting interviews in a semi-structured manner, it’s the interviewers’ responsibility to encourage the respondent to talk freely, making sure that every topic of the interview guide is covered (Polit & Beck 2010, p. 341). The interview guide was prepared by both authors together, after having gotten to know the environment at Guwahati Comprehensive Cleft Care Center. Initially, a pilot interview was conducted. Since the authors, after the pilot interview, found that the interview guide was an adequate support while performing the interview, this interview was included in the study. All of the interviews were conducted jointly.
and each interview lasted for 25-40 minutes. The interviews were recorded and transcribed verbatim.

**Analysis**

Qualitative content analysis is used to identify variations regarding similarities and differences in a text (Lundman & Graneheim 2012, pp. 191-192). Since the experience of supporting can vary from nurse to nurse, the authors considered qualitative content analysis to be a good choice of analysis method. Qualitative content analysis is used to examine and interpret texts, such as recorded interviews. Focus is to describe variations by identifying similarities and differences within the content of the text. The variations are then expressed in subcategories and categories (Lundman & Graneheim 2012, pp. 187, 189).

The data were jointly analyzed, using qualitative content analysis according to Lundman and Graneheim (2009, pp. 187-199). To obtain a holistic picture, the authors initially read all of the data individually. After that, sentences essential for the aim were highlighted, and comments written in the margin. The authors then reflected together on the main content of the text.

Meaning units were identified, condensed, abstracted and given a code. All of the interviews were condensed and coded by both of the authors together. The codes were compared regarding similarities and differences and were sorted into subcategories and categories.
Table 1 Example of meaning units, condensed meaning units, codes, subcategories and categories.

<table>
<thead>
<tr>
<th>Meaning unit</th>
<th>Condensed meaning unit</th>
<th>Code</th>
<th>Subcategory</th>
<th>Category</th>
</tr>
</thead>
<tbody>
<tr>
<td>I use to say something, maybe you have some problem, like physical. Low hemoglobin or sometimes genetic problem and that’s why, so don’t feel sorry.</td>
<td>I try to explain that the deformities is a physical defect.</td>
<td>Providing a medical explanation</td>
<td>Explaning</td>
<td></td>
</tr>
<tr>
<td>We have to always ask them back home what they do. So we advise them whatever is available in their area or in their place like make use of that. First I examine them [...] according to that I just ask them questions. We try to talk to them at their level.</td>
<td>It’s important for me to advise the parents according to their individual level.</td>
<td>Individual advising as a condition of educating.</td>
<td>Individual advising</td>
<td>Education</td>
</tr>
</tbody>
</table>
FINDINGS

The following text is a summary of the nurses’ experiences, as expressed during the interviews and revealed after analysis.

*Table 2* Subcategories and categories

<table>
<thead>
<tr>
<th>Subcategory</th>
<th>Category</th>
</tr>
</thead>
<tbody>
<tr>
<td>Admonition</td>
<td></td>
</tr>
<tr>
<td>Affirmation</td>
<td>Caring actions</td>
</tr>
<tr>
<td>Giving hope</td>
<td></td>
</tr>
<tr>
<td>Involving the family</td>
<td></td>
</tr>
<tr>
<td>Repetition</td>
<td></td>
</tr>
<tr>
<td>Counseling</td>
<td></td>
</tr>
<tr>
<td>Education through interpretation</td>
<td>Educational actions</td>
</tr>
<tr>
<td>Explaining</td>
<td></td>
</tr>
<tr>
<td>Individual advising</td>
<td></td>
</tr>
<tr>
<td>Creating a dialogue</td>
<td></td>
</tr>
<tr>
<td>Sitting down closely</td>
<td></td>
</tr>
<tr>
<td>Bonding</td>
<td>Trusting actions</td>
</tr>
<tr>
<td>Being available</td>
<td></td>
</tr>
</tbody>
</table>
Caring actions

In this category, caring acts that the nurses performed are presented. This category contains the subcategories Admonition, Affirmation, Giving hope, Having a family perspective. The nurses used admonitions against the parents as a working method to achieve compliance; sometimes they also scolded the parents. They expressed a great confidence in their own skills, as demonstrated by insuring parents that they were now in safe hands and would get help. The nurses sought to work from a family perspective; furthermore, it was important for the nurses to encourage and comfort the parents and to, in various ways, be helpful to them.

Admonition

The nurses described that they would encourage the parents to take care of the child in the way that they were told. They stated to the parents what would happen if they cared for the child in the wrong manner; in this way, the nurses highlighted the parents’ responsibility to follow what they had been taught and to make sure that the baby’s health could improve. The nurses described that they often felt disappointed with the parents when the baby’s health didn’t improve, and they were frustrated to see the baby’s poor nutritional status. To admonish was a way for the nurses to make the parents understand the seriousness of the situation and the nurses’ experiences were that the parents listened more carefully after the admonitions.

You have to follow what I tell you and if you are not willing, it’s your own that directive, taking the risk for the child.

Sometimes I got so irritated, you know, and I scold the mother. I said: ‘you’ll get cursed for this, because you’re spoiling this child’s life’. [...] I think nearly all of us, we scold them like that.

Affirmation

The nurses explained that they affirmed the parents by telling them that they now had come to the right place, where they would get adequate help and proper care for their child. All of the nurses indicated great confidence in their professional competence and spoke about being entrusted because of being a medical person. The nurses knew that they had the means to help the parents and they wanted the parents to know this:

I have that confidence that they have come to the right place, you know, so we can teach them or we can help them out. We are here to take care of your child [...] this is the right place where these things can be done [...] we are a medical person [...] we can take care of the baby.

Giving hope

It proved to be obvious that all of the interviewed nurses had a hope that the children would be fine and improve in health. It was clear that the nurses, by reducing parental concerns and by giving them encouragement, tried to convey and give the parents a hope too. The nurses told that they focused on the future of the child, and what it could
be like, when meeting the parents; they looked ahead and tried to get the parents to do the same.

When the lip or palate is repaired you will feel so wonderful. We can make them understand that there is hope, we have that hope.

Involving the family

The nurses spoke of how they asked the parents various questions to learn about the family’s history, living conditions and food habits. The nurses were trying to see the family as a whole, and involved both parents when supporting and teaching. The nurses had found that if the mother alone was responsible for the child’s nutrition, the compliance to given instructions would decrease, since she already was busy in taking care of the household and siblings.

So, like, meaning the cooperation of the whole household [...] even the mother also needs some rest. Because one person can’t be doing the whole thing alone. We call them together and help them understand. I try to gather all that information [...] about the living condition. What happened, from where do you come, what’s his name?

Educational actions

To educate the parents was a big part in the daily work of the nurses. In this category, the nurses’ work in this area is presented. The subcategories are Repetition, Counseling, Interpretation, Explaining, Individual advising and Creating a dialogue. The nurses gave a lot of information to the parents, for example about food and hygiene habits. They emphasized the importance of repeating and explaining the same information many times to make the parents understand properly. The nurses also described the meaning of creating a dialogue and adjust the information to an individual level in order to get the best effects out of the education. Counseling and interpretation were two other parts that the interviewees chose to highlight.

Repetition

The nurses told that much of their time was spent on educating the parents. They talked about the need to repeat the same information many times for the parents to understand it properly. The nurses described further that many of the parents who come are illiterate which means they cannot read or write; many have not been to school. Furthermore, they talked about the importance of having extra time while educating these parents. The nurses experienced that, unless the parents understood the information properly, the parents wouldn’t follow what they had been taught and the child’s health wouldn't improve.

We have to give them time and keep on explaining [...] I talk to them over and over again.
Counseling
An educational method which was revealed during the interviews is counseling. The nurses told that a lot of their time was spent on counseling the parents, which they said, could take a lot of their energy. To counsel the parents properly could make them exhausted, some of them said. One nurse expressed it like this:

If you want to really counsel them properly it takes a lot of your time and energy, it really drains you out.

Education through interpretation
One problem that the nurses who did not come from the state of Assam and didn't speak the local language -Assamese- experienced, was that sometimes they could neither understand or make themselves understood when they educated the parents. Many parents spoke and understood Assamese exclusively, which created communication problems between nurses and parents. The nurses explained that a solution to this problem was to use the housekeeping staff, who was working at the ward, as an interpreter. The housekeeping staff was always close to hand and spoke Assamese fluently.

Sometimes I use the help of some of the housekeeping staff who can speak their language.

Explaining
The nurses spoke about the importance of giving the parents adequate information about the causes of the facial malformation; that it is a physical defect. When they provided a medical explanation, they decreased the parents’ beliefs that the deformities were a curse or a punishment from God for something they did in their previous life.

I use to say something, maybe you have some problem, like physical, low hemoglobin or sometimes genetic problem and that’s why, so don’t feel sorry.

Individual advising
By adapting instruction to an individual level, the nurses experienced that they more easily could reach the parents when educating. They described that many of the families who come to Guwahati Comprehensive Cleft Care Center are very poor and have no money to buy infant formula or other supplements that the child would really need in order to grow in weight and achieve better health. By starting from a family perspective and ask questions about their living conditions and what supplements that are available in their area, they reached a better outcome of the education.

So we advise them whatever is available in their area or in their place like make use of that.
Creating a dialogue

Some of the nurses perceived problems in relation to educational situations. They told that the education sometimes tended to be a one-way communication where the nurses were the only ones talking; to avoid this and to facilitate learning, the nurses emphasized the importance of creating a dialogue with the parents, to create a two-way communication instead.

*Sometimes instead of just speaking, I let them talk to me [...] that is far more better instead of me alone giving lecture.*

Trusting actions

The nurses emphasized in the interviews that one important feature of their work with the parents was the ability of creating trust. This category includes the subcategories Sitting down closely, Bonding and Being available. In order of creating trust the nurses described the importance of creating and developing a relationship with the parents. Through a relationship with the parents, the nurses thought that the care for the children improved and that it was easier to support the parents. They told that they could create and develop this relationship by showing availability and by sitting down closely and talk to the families.

Sitting down closely

By taking the time to sit down closely and talk, the nurses experienced that the parents began to trust them more. When the parents began to trust, their feelings about the child’s situation more easily came up to the surface. The nurses thought that it was a big advantage to know about the parents’ feelings, since it facilitated the planning of supporting actions. Through conversation, the nurses experienced that the parents were becoming more verbally free and open-minded. One nurse expressed it like this:

*You can give time and effort to talk to them [...] they come up with feelings, emotions, anxiety [...] we need to sit down closely and talk.*

Bonding

The nurses valued to bond with the parents. Their experience was that this kind of interaction made it easier for the parents to understand them. The nurses explained that the care of the child was facilitated by considerably if the parents understood them correctly. The nurses also felt that it was important to talk with the parents, not only to them, to create a good relationship.

*To make good intrapersonal relationship [...] we can develop that bonding [...] that is how we can move ahead.*

Being available

On this subject, the nurses strove to prove themselves accessible to the parents. They did this by seeking out the parents at the ward and by calling them. For the same reason,
it was also important for the nurses to quickly assist the parents if they alerted for assistance. The nurses explained that when they turned out to be available and gave time to talk to the parents, they experienced that they could satisfy a portion of what the parents had expected when they came to the Center in need for their child.

*Whenever they call us, we will be there [...] every time we tell them what they need [...] that’s why if we say something they trust.*

**DISCUSSION**

**Discussion of method**

The aim of this project was to describe nurses’ experiences of supporting parents whose children are subjects of the Nutrition Program at Guwahati Comprehensive Cleft Care Center.

The study was based on six interviews which were carried out individually. The interviews aimed for the participants to get in touch with- and describe their experiences in words. There is always a power asymmetry between the interviewer and the interviewee (Kvale & Brinkmann 2009, p. 48-49). This was accentuated as the interviews were carried out jointly, meaning that the interviewers outnumbered the interviewee. All participants approved to be interviewed by two people. An interview guide was used while performing the interviews, as a support for the interviewers to make sure that every topic on the subject was being covered. The first few questions of the interview guide covered topics such as the participant’s nursing education and work experiences. The first questions served as a kind of a warm-up for the other upcoming questions, to create a relaxed atmosphere and making the interviewee more comfortable.

Guwahati Comprehensive Cleft Care Center is an international center and the nursing staff consists of employed nurses as well as volunteers. The staff members come from various countries with various cultures all over the world. To gain a clearer understanding of nurses’ experiences of giving support to parents, the authors chose to exclusively include nurses who had their nursing education in India. This proved to be a good choice since cultural differences, which could have complicated the data analysis, were avoided. The language spoken during the interviews was English and no interpreter was used. It went well to conduct the interviews without an interpreter. Having used an interpreter, however, could have made it easier for the nurses to express themselves in a nuanced way, since they then would have been able to respond in their first language. The purpose of this study was for the nurses to describe their experiences, which can be difficult to do adequately in a second language, in which the vocabulary may be less nuanced. However, to have been able to talk to the nurses directly is considered to have been a more prominent advantage for the study.

Four of the interviews were performed in a secluded cubicle in the ward at Guwahati Comprehensive Cleft Care Center; one was performed in the doctors’ lounge after working hours, and one in the reception area. The cubicle at the ward was considered to be the only place at the center that provided the most privacy during working hours.
However, outside of the cubicle there would sometimes be children making noise. This caused no problems during the interviews since the nurses were used to this kind of disturbance and the interviewers were totally focused on the nurse being interviewed. Still, when transcribing the interviews, it was sometimes difficult to hear what the interviewee said because of the noise from outside the cubicle. According to Kvale and Brinkmann (2009, p. 203), the quality of the recording is crucial for the reliability of a transcribed text. A substandard recording can make it difficult for the author to hear what is being said, which in turn can cause the material to be misinterpreted (Kvale & Brinkmann 2009, p. 203). The, at times, disturbing noises may thus have caused some small parts of the recordings to be neglected and did that the transcription was delayed. However this is not considered to have affected the findings of the study.

If it had been possible, it would have been interesting to perform participant observations in combination with the interviews, which could have provided additional dimensions to the findings. Unfortunately, this was not feasible in the context of this project.

**Discussion of findings**

The findings show how the nurses used different approaches to support the parents of the children in the Guwahati Comprehensive Cleft Care Center Nutrition Program. The nurses performed caring actions by admonishing the parents, by affirming them, by giving hope, by having a family perspective and by being helpful towards the parents. As the nurses educated the parents they repeated the same information many times and they used counseling as an educational method. Sometimes the nurses had to use an interpreter to be able to educate the parents. Furthermore, they provided medical explanations to the parents, they adjusted the education individually and they tried to create a dialogue with the parents while educating. To make the parents trust them, the nurses sat down closely while talking to the parents, and tried to create a bond to them. Moreover, to create trust, the nurses strove to show themselves available to the parents.

At Guwahati Comprehensive Cleft Care Center, the nurses daily met children and parents who were struggling with life changing processes in order to get the surgery. They emphasized the importance to initially create a good relationship with the families; the nurses saw this relationship building as a major advantage, which then would facilitate care significantly. A nurse mentioned that she, by talking to the parents, could create and develop a good intrapersonal relationship. The importance of having a good relationship to the patient is emphasized by Wiklund (2003, p. 55), who present the caring encounter as an essential condition for the caring process to take place.

According to the findings of this study, the nurses attached a great importance to getting to know the whole family and not only the patient. According to Dahlberg and Segesten (2010, p. 119) a patient-focused care includes to make the whole family involved in the care; the caring process must start from a family perspective. The nurses strove to adjust the education of the parents to an individual level; they had found that it was easier to reach out to the parents that way, and that the compliance of the treatment would improve. This way of thinking is confirmed by Dahlberg and Segesten (2010, pp. 183-184) who state that individual adjustment is vital to the caring. The nurse has to meet
each individual with their general knowledge about the situation in mind. By individualizing the care, the chances of compliance increase (Dahlberg & Segesten 2010, pp. 183-184); the patient can more easily absorb the information given and follow the guidelines given during their hospital stay.

One of the most prominent things when meeting the nurses was that they seemed to be very committed to their work. All of them appeared to be very emotionally involved in the care of their patients, including supporting the parents. The nurses talked about the good feelings of succeeding and the bad feelings when not succeeding. Almost all of them told that they felt so happy, excited and pleased when the parents followed their advice and when they saw that the baby’s health improved; the joy that was reflected in their facial expressions during the interviews was difficult to avoid. They also told that they felt so bad, sad, frustrated and irritated when the parents didn’t follow what they had taught and the baby’s health didn’t improve. On the subject of the nurses’ commitment, the nurses’ way of scolding the parents should be mentioned. This approach may be perceived as strange to a Swedish nurse as scolding, in Sweden, usually is associated with something negative. Nevertheless, the nurses at Guwahati Comprehensive Cleft Care Center had found this to be an effective way of action, to make the parents understand the seriousness of the situation.

Based on the findings of this study, it can be stated that the nurses endeavored to find out and take care of the family's resources. Some of the nurses used to ask the parents if there was someone in the family who could help in taking care of the baby so that the mother sometimes could get her necessary rest. Furthermore, the nurses would ask the parents what resources in terms of food that was available around the family home; many of the families could not afford to buy expensive infant formula or other vitally, for their child, necessary food. Within the caring sciences there are some notions that the healthcare should be based on. One of these notions, which hence could be recovered in the findings of this study, was resources. As stated by Wiklund (2003, p. 88), resources comprise everything positive that the human has access to when dealing with suffering, illness and promotion of health. Thus, when making use of the families’ resources, the nurses strove to optimize the parents’ situation, and thereby help the baby.

The nurses had observed obstacles of parental illiteracy, which sometimes could lead to difficulties for the parents to absorb what the nurses taught. Another obstacle was the limited economical resources of many parents, which made it difficult for them to provide for their children and thus help them to improve their nutritional status. Another obstacle that the nurses mentioned was the various spoken languages and dialects. The nurses had found that it sometimes could be difficult to communicate with the parents because of language barriers. The solution to this was for the nurses to frequently occupy one member of the housekeeping staff as an interpreter. Nevertheless, language barriers aren’t an obstacle that occurs exclusively in India. With today's increased globalization and immigration, this obstacle is thought to be shared with nurses all over the world, including Swedish nurses. Wiklund (2003, p. 88) describes health obstacles as all phenomena that prevents human experience of health. As the nurses experienced that the above mentioned prevented them from supporting the parents adequately, these phenomena should be considered as health obstacles.
The nurses highly valued to repeat the same information many times in order to help the parents learn. They wanted to make sure that the parents had understood the information given, in order for the parents to be able to care of their child properly. The nurses were in this context very persistent. According to Jain and Krieger (2010, p. 100), repeating information is a common strategy for medical graduates when facing communication problems due to for example linguistic differences. Can Swedish nurses sometimes be afraid to repeat the same information many times, wanting to avoid sounding too repetitive?

Many Indian parents of children with a facial malformation think that the deformity is a curse, a punishment from God for something they did wrong in their previous life (Weatherley-White, Eiserman, Beddoo & Vanderberg 2005, p. 562). While interviewing the nurses, this statement emerged as one of the biggest health obstacles. Dr. Choudhury, a pediatrician working with the children also confirmed this; many parents have a strong belief that the malformation of their child is God’s will. The nurses told that they, in their education of the parents, had to spend much time explaining that the deformity is a physical defect rather than a curse; a very impressive work. To be able to do that, the nurses had found that they needed the parents to trust them. To gain the parents’ trust, the nurses strove to create a good relationship to them. Within the Swedish nursing profession, the relationship to the patient is highly valued. Wiklund (2003, p. 155) state that the care, if the caring encounter is not prioritized, is at risk of becoming task oriented instead of patient oriented. The nurses at Guwahati Comprehensive Cleft Care Center did take the time to sit down and talk, and they emphasized the importance of sitting down closely in order to bond with the parents.
CONCLUSIONS AND CLINICAL IMPLICATIONS

This study shows nurses’ experiences of supporting parents whose children are subjects of the Nutrition Program at Guwahati Comprehensive Cleft Care Center. Previously, there was a lack of research on nurses’ experiences of supporting parents of children with cleft lip or palate. The findings show that the nurses were very committed to their work and fully strove to support the parents, who were struggling with life changing procedures in order to get their child ready for surgery and thereby improve the child’s health. The nurses described various ways of doing this; however, it was obvious that the relationship to the parents was the most crucial factor for the supporting actions to succeed. To create a relationship to the parents, the nurses strove to make the parents trust them, educate the parents adequately, and performed various concrete caring actions towards the parents.

The findings of this study may be useful to encourage Swedish nurses to take time to bond with patients and families. The Indian nurses were not afraid to set aside time to sit down with the families to create a relationship. Swedish nurses could have much to gain by daring to be more persistent in the communication with patients and families.

Furthermore, the findings of this study may help to increase the understanding of how nurses perceive their work in supporting next of kin; the findings may be interesting to nurses all over the world. To obtain a wider understanding of nurses’ experiences of their complex work within this area further research, such as participant observations, is encouraged.
REFERENCES


Gill, R. (2011). Nursing Shortage in India with special reference to international migration of nurses. Social Medicine, 6(1), 52-59. pp. 54


Letter of information
Our names are Julia Hjalmarsson and Karin Kjernald. We are students at the School of Health Sciences at the University of Borås, Sweden. Our study program is Bachelor of Science in Nursing. We have been granted a scholarship to carry out our bachelor thesis in India. The study deals with nurses' experiences of educating and supporting parents within the Nutrition Program at GC4. The name of the study is “Nurses’ experiences of educating parents of children with cleft palate - a minor field study”.

To perform the study we are looking for six to eight Indian, English-speaking nurses, involved within the Nutrition Program who are willing to participate in an individual interview. The estimated time to complete each interview will be approximately 30-60 minutes. Following the informants approval, the interview will be recorded. An interview guide with beforehand prepared questions will be used. The nurses will also be able to freely talk about their experiences. The information given by the informants will be handled confidentially. The collected material will only be read and handled by the authors and the supervisor at the School of Health Sciences at the University of Borås, Sweden.

The study will be written in English, and all participants will be given the opportunity to take part of the finished work. The informants will be able to, at any point during the study, withdraw their participation without further explanation.

We hope to share your experiences.

Best regards,

Julia Hjalmarsson
julialinneahjalmarsson@gmail.com

Karin Kjernald
karinkjernald@gmail.com
Nurses experiences of educating and supporting parents

- How come you decided to work for Operation Smile?
- What do you feel when you meet the children with cleft lip or palate?
- What is important for you when you meet the parents/guardians of these children?
- How do you give information to/teach the parents/guardians? What do you say? What kind of information do you give?
  - Can you tell us about an example? What did you do? What did the parents/guardians do?
- Do the parents/guardians follow your advices? Why or why not?
- How do you create trust/confidence?
- Do the parents/guardians trust you?
  - Can you tell us about an example? What happened?
- What do you think is the biggest problem for the parents/guardians related to the malformations of their child?
- Do you think that the parents/guardians need emotional support?
  - Why/why not?
  - If so, in what way can you support the parents/guardians?
  - Can you tell us about an example?

- Are there any factors that complicate your work?
  - In what way, how does it affect you?
  - If you may need any support for your own behalf, what are the opportunities?
- What are your visions for Nutrition Program?
  - What do you think the nursing profession within the Nutrition Program will look like in the future?