Parents’ experiences of family-centered care in the Special Care Baby Unit (SCBU)

by

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A dissertation submitted in partial fulfillment of the requirements for the Masters (Honours) in Midwifery studies

University of Malta

June 2006
To

my dear husband

Luciano
DECLARATION

I hereby declare that this dissertation is entirely my own work carried out as part of the Masters (Honours) in Midwifery studies.

Rita Pace Parascandalo
I would sincerely like to express my gratitude to my supervisor, Ms Rita Borg Xuereb MSc, PQDip. Midwifery Education, Dip Ed (Adult), RM, RN for her guidance and support throughout the compiling of this study.

I am also grateful to all the parents who very willingly participated in this study, surely without them this study would not have been possible.

I am grateful to my brother-in-law, Mr Kevin A. Cassar, for proof reading this dissertation.

Special thanks also goes to my shift colleagues at SCBU for their support and interest shown in my work.

I am also thankful to my family, especially my parents, who always supported me particularly when times seemed rough.

Heartfelt appreciation undoubtedly goes to my husband for his endless encouragement, support and for being beside me all along the way.
This study explores parents' experiences of their participation and involvement in the care of their newborn in the local Special Care Baby Unit (SCBU). The literature review discusses relevant literature surrounding the concept of family-centered care which is central to this study. An interpretive phenomenological research design was used in this study. Semi-structured interviews were used to collect data from six couples whose infants born at 37 weeks gestation or more required care in SCBU for minor problems. Interpretive phenomenological analysis resulted in themes and sub-themes into which the findings have been grouped. Results indicate that parents experience various reactions to their child's hospitalization in SCBU, which reactions are influenced by different demographic issues. Parents' participation issues as in care-giving activities, barriers to participation and bonding have been shown to vary according to the baby's stage of hospitalization and vary between mothers and fathers. Staff attitudes and behaviours have been shown to influence the parents' experiences namely in their information and participation needs. Visitation issues relating to the parents timing and duration of their visits in SCBU were explored and differences between mothers and fathers visiting have been found together with changes in parents visiting over the course of the child's hospitalization. Other visiting issues included visiting by siblings and by relatives in SCBU. The local visiting policy was extensively discussed and parents offered various suggestions on how to improve the current policy. These findings have revealed the nature and extent to which various issues relating to family-centered care are being practised and experienced by parents locally. Consequently, results have helped to suggest recommendations for further studies and potential implications for practice which would help adopt a more family-centered approach to care in the local SCBU.
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INTRODUCTION
Family-centered care is nowadays acknowledged as an optimal approach to care particularly in neonatal and paediatric nursing. It is a philosophy of care that incorporates ‘supporting the integrity of the family and individualizing care to promote individual and family health’ (May & Mahlmeister, 1990 p. 22). Nonetheless, nursing literature suggests that nursing practices may not always reflect this approach to care.

Family-centered care is valuable in helping families whose infants require hospitalization, cope with the stress, fear and altered parenting roles that may accompany their infant’s condition and hospitalization (Malusky, 2005). This approach to care has also been found to reduce the separation of an infant from his parents, improving parental skills, increasing their sense of control and self efficacy (Neil, 1996; Bialouskurski, Cox & Wiggins, 2002). In neonatal nursing, family-centered care is also said to be essential for the promotion of bonding between the infant and the parents and for optimal development of newborn infants (Casey, 1995; Gale & Franck, 1998).

Being a midwife working in the local Special Care Baby Unit (SCBU) for two years has evolved my interest into this area of study. My main preconception, gained from my experience of working in this unit, is that certain characteristics associated with family-centered care are being practised locally but the extent to which such care is experienced by parents is unclear, possibly due to a lack of a formal family-centered care policy. In this study I used an interpretative phenomenological design, which although novice to this type of research, I intended to explore nursing practice in the local setting by looking into the parents’ experiences of their participation and
involvement in the care of their newborn while in SCBU. This is a way of evaluating the care in SCBU for the presence of characteristics which are known to be central to the practice of family-centered care. The findings may help encourage nurses and midwives working in the SCBU to reflect on the manner in which they approach families and to what extent they involve them in the care of their newborn (Malusky, 2005). Accordingly, it is anticipated that the study findings will help to identify areas for improvement in practice and aid in the implementation of a more family-centered care approach in the local SCBU (Casey, 1995). Such findings could then be used to formulate a family-centered care policy which would help guide practice in the local setting.

Incorporating family-centered care into daily professional practice can enable midwives and nurses to improve the emotional and physical well-being of each family they encounter. Family-centered care can broaden the scope of practice by promoting communication and meaningful relationships to facilitate improved health for infants and their families. The individualized delivery of family-centered care can greatly enhance the unique experiences of families with infants in the SCBU (Malusky, 2005).

Special Care Baby Unit (SCBU) and Neonatal Intensive Care Unit (NICU) will be used interchangeably since locally this unit is called SCBU while in most countries and consequently in the literature it is referred to as NICU.
CHAPTER 2

LITERATURE REVIEW
AND
THEORETICAL FRAMEWORK
2.1 Introduction

Family-centered care (FCC) is a multifaceted concept which has evolved over the past 50 years and became a central tenet of neonatal and paediatric nursing (Smith, Coleman & Bradshaw, 2002). However, this concept is still poorly defined and there seems to be no clear agreement on what constitutes FCC (Coyne, 1995; De Beresford, 1997; Hutchfield, 1999). Smith et al (2002) suggest that an overarching contemporary definition of FCC could be seen as:

‘The professional support of the child and family through a process of involvement, participation and partnership, underpinned by empowerment and negotiation’ (Smith et al, 2002 p.22).

Hutchfield (1999) argues that parental involvement, participation and partnership with parents are surrogate terms to FCC. Coyne (1995, 1996) adds that the literature suggests that these terms are often considered as synonymous and are used interchangeably. FCC has also been viewed as a hierarchy which begins with parental involvement and culminates in FCC (Ahmann, 1994a, 1994b). Other authors identified that parental involvement, participation and partnership are central elements in FCC (Arango, 1990; Casey, 1993; Palmer, 1993; Evans, 1994) and in fact, all three terms are included in the definition later put forward by Smith et al (2002).
The following literature review attempts to explore issues surrounding FCC in the neonatal intensive care unit (NICU). Namely it discusses: the evolving patterns of family involvement in the NICU, the theoretical framework chosen for this study, the parents' reactions to NICU hospitalization, parents' participation and visitation issues together with staff behaviour and relationship with parents in the NICU. Although the literature about FCC is relatively abundant, it is mainly narrative in nature and is still an under-researched area of study particularly in NICUs.

2.2 Historical perspective – evolving patterns of family involvement

Historically, until the 1970s, neonatal units excluded the parents and families, as they were considered too much of an infection risk to allow them to have any great access to their infants (Laurie, 1995). Parents, wearing masks and gowns were cast in the role of visitors, with the connotation of being invited in, rather than having a right to come and go at will (Vine, 1995). However, a very important study done by Barnett, Leiderman, Grobstein and Klaus (1970) demonstrated that infection rates in neonates did not increase when parents were allowed into the nursery and the increased parental contact was beneficial to their confidence and commitment to their child.

Similarly, the seminal work by Bowlby (1971) followed by Klaus and Kennell (1976) continued to highlight the social and emotional needs of parents and since then there has been a gradual progression from encouraging family visiting to parental participation and FCC (Beresford, 1997; Spencer & Edwards, 2001). Therefore, such
evidence led to greater flexibility in hospital policies which then attempted to expand the role of parents in caring for their newborns (Davis, Mohay & Edwards, 2003). The emergence of infant developmental research and its impact on care practices also started in the post war years and such research continued to demonstrate the fundamental importance of the parent-infant interactions to the developmental outcomes of such infants (Dobbins et al, 1994; Davis et al, 2003).

2.3 Theoretical framework – Family Systems Theory

The elements of FCC have been discussed in relation to intensive environment by Rushton (1990). When restated and adapted to apply directly to care given in the NICU setting they include 8 elements (appendix A) where one central element is that of recognizing the family as the constant in the child’s life, since service systems and personnel within those systems fluctuate (Handmaker & Stewart, 1988; Brown, Pearl & Carrasco, 1991; Dobbins et al, 1994; Hurst, 2001; Pearson & Anderson, 2001). Some authors argue that although a newborn baby may not have yet ‘lived at home’, he/she is still a part of the family and care must focus on supporting the family as a whole (Sydnor-Greenberg & Dokken, 2000; Pearson & Andersen, 2001) since the child is only a transient member of the NICU (Fenwick, Barclay & Schmied, 1999). According to Tosh (2001), the concept of FCC is to view the family as a system, considering its needs as a whole, focusing on all members even when care is only directed at one. Families are dynamic complex systems which are acted upon by many forces to which they respond more or less adaptively depending on their resources, and their definitions and perceptions of these events. Families’ responses
to these events create a dynamism, which results in families being ever changing entities. Thus, effective family-centered services must recognize and be sensitive to this changing nature of the family which calls for an approach which is flexible but yet responsive to the family's changing needs (Thurman, 1991). The assessment of the family from a systems' perspective allows the understanding of family dynamics and the family unit's strengths and weaknesses, which are very important aspects of family functioning (Casey, 1996; Wong, 1999).

In 1954, Bowen introduced the family systems theory, which is a natural systems theory of the family and provides a conceptual framework for recognizing the impact of relationships between family members, within organizations and in society (Wong, 1999). In family systems theory, the emphasis is on the interaction between the members, such that a change in one family member will affect every other member of the family, as well as the family structure itself (circular causality) (Ashwill & Droske, 1997; Casey, 1996; Friedman, 1997; Wong, 1999). Thus, family systems have interrelated elements and structure. The elements of a system are the members of the family. Each element has characteristics; there are relationships between the elements; and these relationships function in an interdependent manner. All of these create a structure, or the sum total of the interrelationships among the elements, including membership in a system and the boundary between the system and its environment (Morgaine, 2001). According to Friedman (1997), families grow and evolve so that the system becomes increasingly more discriminate, articulate and complex.
After reviewing several theories which could provide a theoretical framework for this research study, the family systems theory was considered the most appropriate as it allows for the exploration of the experience of family-centered care from the spouse subsystem (i.e., the parents) of the family, while their child is in the SCBU, as intended by the research question.

Family systems theory originated from the general systems theory which was developed by biologist Ludwig von Bertalanffy in 1936. Gillies (1982) refers to systems theory as a 'grand theory' that has wide scope and many applications. Systems theory involves the basic idea that objects in the world are interrelated to one another (Whitchurch & Constantine, 1993). The theory is in part a response to positivist thinking about applying the principles of natural sciences models to social science. Human beings are different from the inanimate subject matter of the natural sciences, and therefore theorizing and research about humans requires a different perspective than that taken by natural science and later positivists (Friedman, 1997). This systems model breaks down the linear cause and effect model of the natural sciences, which is consistent with the medical model, because how individual elements react within a family is due to a variety of interacting factors rather than a simple linear fashion (Friedman, 1997). During the last 30 years, systems theory gained widespread acceptance in the health-care field (Danielson et al, 1993; Friedman, 1997). Hence, general systems theory most importantly expanded scientific thought from a simplistic view of direct cause and effect (A causes B) to a more complex and interrelated theory (A influences B, but B also affects A) (Danielson, Hamel-Bissell, Winstead-Fry, 1993; Friedman, 1997; Wong, 1999).
The Bowen family systems theory suggests that the human family is a multigenerational, natural, living system and that the emotional functioning of each member of the system affects the functioning of the other members in predictable ways (Comella, 1999). Families are considered systems because they are made up of interrelated elements or objectives, they exhibit coherent behaviours, they have regular interactions, and they are interdependent on one another (Morgaine, 2001).

The systems view of families provides a method for understanding the interaction and interdependence of individuals within a family, as well as the family's interaction with other systems (Casey, 1996). Danielson et al (1993) argue that family interactions are complex and are influenced by the individual family members and by society. The interactions of the family which are of interest to this study relate to the interactions between family members particularly the parents' interaction with their new family member, the infant, and also their interaction with health care staff. The latter can be seen as an interaction between two systems; the family and the health care system.

Dobbins et al (1994) claim that implementation of FCC takes on an additional challenge in the NICU setting, as opposed to settings for older paediatric patients, because family roles and routines are emerging in relation to the new infant and are not firmly established prior to the child's admission. FCC encourages the inclusion of the family in the planning and provision of care as it acknowledges the infant's family as the best people to care for and nurture their child (Fenwick et al, 1999; Galvin, Boyers, Schwartz, Jones, Monney, Warwick & Davis, 2000; Hurst, 2001). This model of care embraces the philosophy that care of the infant in the SCBU should be a three-way interaction, where parents take a central role and are seen as
equal partners with health care professionals (Fenwick et al, 1999). However, despite all this, Hurst (2001) argues that to date FCC is essentially an idea lacking a foundation based on research, identified theories and models of practice.

2.3 **Parents’ reactions to infant’s hospitalization in NICU**

Clearly the hospitalization of an infant in the NICU creates a stressful situation for virtually any family (Fenwick, Barclay & Schmied, 2001; Bialoskurski et al, 2002; Saunders, Abraham, Crosby, Thomas & Edwards, 2003). Families are thrust into unfamiliar territory and are confronted with technology and terminology which is foreign to them (Thurman, 1991). The sights and sounds of the NICU, the infant's physical appearance, medical equipment and relationships with health care professionals in the unit all affect parenting behaviour (Pearson and Anderson, 2000). Parents must cope with feelings of disappointment when they do not achieve their expected pregnancy outcome and fear about the survival of their child and about the potential sequelae of their illness (Wereszczak, Miles, Holditch-Davis, 1997; Pearson & Anderson, 2000; Ward, 2001). Spencer and Edwards (2001) argue that not only must parents adapt to a high-tech hospital environment but they must also begin their parenting experience in a very public place.

The time an infant spends in the NICU is a time of not only intense medical needs but also an unusually sensitive time for parents and infants to begin forming a bond that will affect the infant life-long (Haut, Peddicord & O'Brien, 1994; Gale & Franck, 1998). The experience of stress and separation for parents and their sick infants in
the SCBU disrupts the process of parent-infant attachment and may increase the risk of parenting disorders (Pearson & Anderson, 2000). Gale & Franck (1998) from their study suggest that infants who are separated from their parents and the latter are not involved in care, may be at a greater risk for parental abuse, neglect, failure to thrive syndrome and delayed physical and/or intellectual developments.

In a study by Curran, Brighton & Murphy (1997), 60 parents whose infants had been admitted to an NICU in Essex UK, at 32 weeks or less answered a questionnaire which was designed to delineate the psychoemotional problems encountered by parents during their infant’s hospitalization. The most significant negative emotions expressed by parents included; fear (76%), anxiety (75%), stress (51%) and depression (33%). However, these emotions decreased progressively during the child’s stay in hospital. On the contrary, more positive emotions were expressed more toward the end of the child’s hospitalization. These included; joy (51%), confidence (29%) and hope (28%). Although the study findings are similar to those found in other studies, the results from this study cannot be generalized primarily due to the small sample size used. Also, inclusion criteria, sampling technique used and demographic data which could have influenced the results are not included. The fact that both parents were questioned is an asset to the study although responses were not attributed according to gender and so comparison between mothers’ and fathers’ answers cannot be done. This study also failed to explore what affected the parents’ responses, whether these related to the care they received in the SCBU or the SCBU environment itself, etc. A more qualitative study could have helped to elicit more in-depth data.
A similar but qualitative study was done by Wereszczak et al (1997) where 44 mothers of three year-old prematurely born children were interviewed, using semi-structured interviews, as part of a longitudinal study. The aim was to examine how mothers of these children retrospectively recall their responses to their infants' hospitalization in the NICU. The findings demonstrate that mothers vividly reported memories of stress related to the appearance and behaviour of their infants. The pain and procedures the infants endured were also considered very stressful. Alterations in their role as parents was also identified as being stressful especially the separation from their infants, which was identified by most mothers as the most difficult aspect of the hospitalization. Mothers also found it troubling that they were unable to participate more in the care and nurturing of their infant. Although this study is limited by its relatively small sample, it also lacks what most research in this field of study lack, that of including the fathers and their responses to having their infant in NICU. In addition, sampling details and demographic data which could have influenced the results are not included. Yet, this study emphasizes the stress experienced by mothers when their child is admitted to NICU.

A more recent study done by Nystrom and Axelsson (2002) looked into the mothers' experience of being separated from their baby when he/she was in SCBU. A hermeneutic phenomenologic design was employed where 8 Swedish mothers whose full-term baby required between two to four days care in an NICU during the first ten days of life for a mild illness. Unstructured interviews were conducted by the researcher, one to two months after discharge from hospital in the mothers' homes. The understanding of the mothers' experiences and reflections was presented within the three themes of 'being an outsider', including sub-themes of despair,
powerlessness, homelessness (not belonging) and disappointment; ‘lack of control’, including sub-themes of emotional instability, threat, guilt and insecurity; and ‘caring’, including more positive sub-themes of thrust, love, relief, closeness and (seeking) explanations. Most of the thirteen sub-themes were related to the baby, NICU environment and staff. It was concluded that the mothers felt separation was an emotional strain, but adapted to this unexpected event. Although this study was done with full-term infants as opposed to the other studies discussed above (Curran et al, 1997; Werszczak et al, 1997) relating to preterm infants in the NICU, the findings are similar suggesting that the mothers’ reactions to their child’s hospitalization in the NICU are relatively similar irrespective of the child’s gestational age. Fathers have again been excluded in this study. Details of the sampling method used and whether interviews were done on a one-time basis or if they were repeated were not included in this study.

Family-centered care in the NICU is proposed as a way to reduce parental stress, positively affect the parent-infant relationship across time and for optimal development of SCBU infants (Thurman, 1991; Gale & Franck, 1998; Franck & Spencer, 2003). The reactions to SCBU admission found in the literature (Curran et al, 1997; Wereszczak et al, 1997; Nystrom & Axelsson, 2002) lead to the need to provide services in the SCBU which are family-centered rather than primarily infant centered, as may often be the case. Thurman (1991) acknowledges that this is not to suggest that the medical and developmental needs of the infant should be de-emphasized but rather that the emotional and psychological needs of families must be given equal concern and that the infant’s needs be interpreted within the family context.
Recommendations from the findings of the studies discussed above (Curran et al, 1997; Wereszczak et al, 1997; Nystrom & Axelsson, 2002) suggest that the effects of an SCBU admission can be attenuated by nurses and midwives working in the SCBU who have the most contact with the parents. Hence, an important role for neonatal nurses / midwives is to be able to assess the reactions and responses of these parents and to help them deal with this event as effectively as possible while preparing them for their new parental role. Lau and Morse (1998) suggest that nurses can incorporate into their daily nursing practice strategies that allow the parents to understand and become involved in the care of their infants. This would help to increase their feelings of self-confidence and efficacy (Bruns & McCollum, 2002).

2.5 Parents' participation and visitation

As parents learn to adjust to the NICU environment, they must be encouraged to spend time with their infants and take a more active role in the baby's care and so facilitating parental role development (Vine, 1995). According to Laurie (1995), parents of even the most critically ill neonate can provide some care for their child. Parents may be insecure about their own abilities or reluctant to establish a relationship with the sick infant in case the child should die (Kenner, 1992). For this reason, Redman (1993) argues that it is important not to push the parents into participation until they indicate that they are ready to do so.

The importance of parent visiting and involvement in infant care has long been recognized, yet few recent studies have examined parent visiting patterns and
participation in infant caregiving. One such study was published by Franck and Spencer (2003) who carried out a descriptive observational study to ascertain the duration and frequency of parent visiting to the SCBU, to identify the extent to which parents participate in caregiving activities and to identify factors associated with parents' participation. This was done in a London tertiary care teaching hospital where data collection took place between 8am and 7.30pm on Tuesday, Wednesday, Friday and Sunday of one randomly selected week each month for 3 consecutive months, resulting in a total of 12 days. This provided a representative view of visiting patterns throughout the week and the time chosen coincided with the nurses' shift pattern as well as the most common time for parent visiting. Data were collected on 110 infants and their parents representing 16% of total annual admissions to the NICU. The sample was representative of the unit population with respect to gestational age and respiratory support.

Data were collected for all infants who resided in the NICU for a full day excluding new admissions on the day of data collection. Nurses in the NICU were asked to record information about parent visiting for those infants for whom they were caring on the data collection days, including infant demographic and medical condition, the timings that the parents visited and caregiving activities performed by parents during their visits. Linear (frequency and duration of visiting) and logistic (caregiving activities) regression analyses were performed to identify factors associated with parental visiting and participation in caregiving activities.

Franck and Spencer (2003) found that mothers visited more frequently (85% vs 45% of possible days) and for longer than fathers, but visited less frequently if the infant
had other siblings, the infant was older than one month, or if fathers made fewer visits. On the other hand, fathers visited less frequently if the infant was older than seven days and more frequently if the mother visited more frequently. No difference in parental visiting occurred based on day of the week. An earlier survey study done in 1994 by Dobbins et al, with 207 parents of infants who had experienced an NICU admission at the University of Virginia Children’s Medical Centre, found that the mean frequency of parental visits to the SCBU was once a day and that the length of hospitalization and distance of the hospital from home, greatly influenced frequency of parental visits. Such associations were not demonstrated by Franck and Spencer (2003) results, yet these findings together with factors such as unstable domestic arrangements, lack of transport, cost of transport, demands of work, care of siblings and parental immaturity, have also been associated with decreased visiting by parents in three earlier US studies (Giacoaia, Rutledge & West 1985; Brown, York & Jacobsen, 1989; Lewis, Bendersky & Koons, 1991).

Franck and Spencer (2003) also found that all mothers and most (96%) fathers carried out social activities, such as talking, stroking or holding during their visits. Over 75% of mothers engaged in infant cleaning and feeding activities during their visits in contrast with less than 20% of fathers. Mothers’ participation in infant feeding was best predicted by the duration of their visit and their participation in infant cleaning. Fathers’ participation in infant feeding was only related to their participation in infant cleaning and not to their visitation. In Dobbins et al (1994) survey, 89.8% of parents stated that they held their infant, 79% provided toys or clothing, 18.9% completed feeding, bathing or diapering, 18.4% gave medication or medical treatment.
Both studies (Franck & Spencer, 2003; Dobbins et al, 1994) provide an insight into parental participation and visitation in the NICU. However, although there are various similarities in their findings, comparison between the two studies is difficult primarily because of the different study designs used, a significant time gap between the two studies and being done in two different countries where different care practices and visitation policies could have influenced the results. The findings in both studies must be interpreted with caution since each were conducted in one NICU setting which makes generalizations more difficult. Since neonatal unit staff carried out data collection in Franck and Spencer (2003) study, inter-rater reliability was not determined. Under-reporting or over-reporting parent visiting and infant contact may have occurred, although staff received ongoing instructions and support from one of the researchers throughout the data collection period. In Dobbins et al (1994), findings may be limited primarily by the non-random sampling used and what parents said regarding their visitation may not have been the true picture. Also the survey does not distinguish between mothers' and fathers' responses and so comparison between mothers' and fathers' responses, which have been shown to be significantly different by Franck and Spencer (2003), cannot be done.

An important finding is that duration of visit rather than frequency of visiting best predicts maternal involvement in activities (Franck & Spencer, 2003). This suggests that parents with limited ability to visit perhaps should be encouraged to visit less frequently, but to stay for longer periods because they are then more likely to engage in caregiving activities. Furthermore, the frequency, duration and quality of parent visits may be enhanced by encouraging parents to visit together whenever possible. Franck and Spencer (2003) suggest that audits of parent visiting patterns and
involvement in caregiving activities which include parents' views are a valuable tool
for ensuring awareness of the particular characteristics and needs of parents,
identifying areas of practice that may require improvement, and suggesting
opportunities for enhancement of care.

Glen (1989) argues that effective care planning needs to consider that each parent
will have differing capabilities and will wish to be involved at different levels, not
just in comparison to other parents, but also to their own partner. Laurie (1995) adds
that diverse family and cultural patterns that influence involvement in care should be
acknowledged and respected. According to Lee (2004), families should be given a
choice as to the extent of their involvement and that it is important to acknowledge
how anxious parents can be when their child is admitted. Coyne (1995) suggests that
this increased parental anxiety may serve to decrease the amount of involvement that
some parents feel able to commit themselves to initially. Consequently, Glen (1989)
suggests that an effective way to ensure that parents become involved at their own
level, is to allow them to set their own goals which are more likely to be reached and
bring beneficial results to the family, then those set for them.

Another issue relating to parental participation in the NICU is the involvement of the
father. Unfortunately, the father's role in infant care is still a relatively under-
researched area. Vine (1995) argues that this may be because tradition appears to
have dictated that the father should have no part to play in caring for his newborn
child. His role has been that of a wage earner and to give emotional support to the
mother. However, Schaffer (1990) highlights that there are now no operative
biological constraints that necessarily make the mother the principal care-giver.
Gender-role segregation is no longer as absolute as in the past so that parents may be encouraged to participate equally in the care of their infant. Bedford and Johnson (1988) suggest that this is an area that is worthy of further discussions, considerations and qualitative research in order to find ways of successfully utilizing the father as an active, child caring parent on the NICU.

According to Laurie (1995), for both parents to be involved in the care of their infant it is important to ensure that they are able to visit as frequently as they wish. However, this is easier said than implemented in practice because NICUs have visitation policies. Cuttini, Rebagliato & Bortoli (1999) compared SCBU visitation policies across 8 European countries; France, Germany, Great Britain, Italy, Luxembourg, the Netherlands, Spain and Sweden. One hundred and twenty-three SCBUs selected at random were recruited. Cuttini et al (1999) found that parents are admitted without limitations of any sort in Great Britain, Luxembourg and Sweden; in Italy and Spain fewer than 20% of units allow unrestricted visiting, while France, Germany and the Netherlands range between these extremes. Policies regarding grandparents and siblings are considerably stringent with Great Britain and Sweden being the most liberal and visiting by grandparents seems to be less tolerated than visiting by siblings.

Almost all units in Great Britain, the Netherlands, Sweden and Luxembourg regularly allow parents to be present during the doctor's examinations and routine medical procedures, while policies are less liberal when emergency, often more invasive manoeuvres are involved. Again Italy, Spain, France and Germany seem to follow a different policy with a more conservative approach. These results show the presence
of wide variations in visiting policies across countries. According to Cuttini et al (1999), such variations broadly correspond to a north-south contrast, with units from northern countries being more receptive to family involvement than the southern Mediterranean ones, with Germany, France and the Netherlands occupying an intermediate position. It could be argued that since the importance of parental participation in the care of SCBU infants is increasingly being recognized, then these findings have implications for neonatal intensive care organization and policy which should be flexible, accessible and responsive to the needs of families (Thurman, 1991; Brown et al, 1991).

Griffin (1998) argues that no NICU policy evokes more conflict than the visitation policy. Tensions often revolve around, visiting hours, who may visit, the number of visitors allowed at the bedside at a time and inconsistent enforcement of existing visitation policy (Griffin, 2003). A common debatable issue in SCBU visitation is who is allowed to visit and the question revolves around whether siblings and grandparents should be allowed into the NICU. Laurie (1995) identifies that siblings of a sick newborn should not be forgotten in the midst of the family crises as their routine may be disrupted. She agrees that siblings should be encouraged to visit the NICU as, apart from forming a strong family unit, older children tend to focus on the positive aspects of the baby and not on the equipment that adults concentrate on, thus helping parents’ acceptance of the new baby. Yet, research which includes siblings is lacking and none has been encountered.

It has already been discussed that having a child in NICU is a stressful event. Consequently, every parent no matter how well-developed their own personal
resources, depends to some extent on the support of others within their social system to cope with this situation (McHaffie, 1992). Miles, Carlson and Funk (1996) argue that grandparents occupy a special place in support networks and their role is recognized following the birth of any child, however there is a paucity of research in the area of babies who require hospitalization. McHaffie (1992) carried out a study exploring such sources of support for families of very low birth weight infants in Scotland. The sample for the main study was drawn from the 7 largest neonatal units in Scotland, 2 in Glasgow and another 5 in Aberdeen, Bellshill, Dundee, Edinburgh and Irvine. Recruitment took place over 6 months in 4 of the units and over 12 months in the remaining three. One hundred ninety eight (198) nurses, 33 doctors and 93 eligible families (181 parents and 242 grandparents) took part in the study. Postal questionnaires were designed specifically for this research and made use of simple rating scales in order to investigate opinions relating to current visiting policies and lay sources of support, particularly the role of grandparents. Tools and procedures were all piloted and data was analysed using SPSS (version 10 for windows).

The findings show that nurses recognized that the unique function of the grandparents to be one of support and enabling parents to cope, grandparents can ‘act as a stress valve’ and they ‘should be more supportive than protective’. In general, the doctors’ views were congruent with those of the nurses and considered emotional support to the parents as a key role of grandparents (McHaffie, 1992). The overwhelming majority of parents looked for emotional support from the grandparents. Many comments reflected the general feeling that grandparents were best in the background, available when needed, and only to become actively involved at the
parents’ request. Visiting the baby was one expression of support parents looked for from grandparents which demonstrated interest and involvement. There were clearly many variations both between and within families for what was found to be supportive. For some, maintaining a sense of hope and future was important. For others, simply showing that the infant and parents were high priority in their lives was reported (McHaffie, 1992).

Maternal grandmothers were clearly key figures in terms of support in the perceptions of both mother and fathers. Expectations of their involvement were higher and their actual support was greater than that of other grandparents. Such a finding was also found by Affleck and Tennen (1991) and Coffman, Levitt and Deets (1991) in their studies. Mothers found their own parents more supportive, but fathers assessed the two grandmothers and the two grandfathers similarly, with the former more supportive than the latter. It seemed important to understand the nature of the support grandparents actually provided. Over the whole period of the baby’s hospitalization there was a clear priority given to the role of listening and emotional support while practical help was of less importance (McHaffie, 1992).

One hundred and sixty eight (92%) grandparents visited the baby in the first month, with only fourteen not managing to visit. After one month, visiting became a more frequently mentioned way of helping. The grandparents themselves considered their main role to be the provision of emotional support. Of the 588 comments made about the help grandparents felt they had been able to give, only about a third specifically mentioned a practical, tangible form of support such as caring for siblings, giving financial aid, providing meals or accommodation. More grandmothers than
grandfathers on both sides were seen to be offering help and a number of grandfathers commented on the more active role of their spouses. There was a tendency for both parents to be more supportive where this was a first baby and when they lived within 20 miles of the unit (McHaffie, 1992). Including the views of all those concerned helps to strengthen the findings. Generalizations from this study may be difficult since responses are particular not only to the setting but also to NICU hospitalization of very low birth weight infants.

Griffin (1998) argues that parents should be allowed to define their own support persons and only they decide who can visit their infant. McHaffie (1992) adds, that to make blanket rules such as those commonly seen regarding involvement of grandparents in NICUs is clearly denying their reality of society as we know it. Implementation of a more liberal visitation policy requires communication and negotiation with families who have varying needs and ways to support them must be found. The visitation policy should offer guidelines, not rules, for families (Griffin, 1998). A liberal visitation policy may be challenging to the staff but a conservative or restrictive policy is often frustrating to families of hospitalized infants (Griffin, 2003).

2.6 **Staff behaviour and relationship with parents**

Family-centered care changes the nurse’s role from one where the nurse is very much the hands-on expert, to one where the parents are regarded as hands-on experts in relation to their child and viewed as an integral part of the caregiving team (Heerman
& Wilson, 2000). The nurse’s or midwife’s role therefore, becomes that of a facilitator, educator and support to the child and family (Ahmann & Johnson, 2000). Heerman and Wilson (2000) emphasise that negotiation and sharing of power, knowledge and skills are essential for true parental participation and implementation of FCC requires mutuality in the nurse-parent relationship.

Nurses appear to have different perspectives towards parent participation (Cardoso, 1991; Dobbins et al, 1994). McGrath (2001) argues that parents are still often seen as intruders into this highly technical environment of the NICU. Others, add that some nurses view this approach as challenging their nursing role and threatening their identity and authority (Coyne, 1995; Fenwick, Barclay & Schmied, 2001). According to Ahmann and Johnson (2000), those nurses who have a positive attitude towards partnership consider that there is always something that a child’s family can do and are more willing to involve the family in care (Casey, 1995). Yet, staff paternalistic behaviour resulting in a lack of parental involvement has continued to be noted by researchers undertaking qualitative studies on parents whose baby has received neonatal intensive care (Heerman & Wilson, 2000; Fenwick et al, 2001; Hurst, 2001).

According to Spencer and Edwards (2001), professionals and professionalism are received by the parents as the focus of power and control whilst parents conduct themselves as lay people. Neill (1996) says that parents may adopt a passive role and readily transfer all aspects of care to the professionals without question, relinquishing a duty for which they have spent many months preparing. The family is vulnerable and may honestly feel that they are greatly inferior to the substitute parent that the
nurse may have become in their eyes and recognize the need to depend on the healthcare professionals' abilities (Spencer & Edwards, 2001; Franck & Spencer, 2003). Consequently, the parents' respect for professional knowledge and skills legitimizes paternalism and minimizes potential parent involvement (Heerman & Wilson, 2000) which interferes with the development of parent-infant relationships and restricts communication between parents and professionals (Neill, 1996).

The literature indicates that the nature and extent of parental participation is presently under nurses' control (Heerman & Wilson, 2000; Franck & Spencer, 2003) since their attitudes and behaviour create a climate that can either support or impede the amount of parents' participation in their infants' care (Espezel & Canam, 2003). Knowledge about nurses' behaviours and parents' participation is relatively limited but two such studies which have been encountered in the literature will now be discussed.

Heerman and Wilson (2000) carried out a study to explore and describe nurses' experiences while working with parents and infants receiving FCC in an NICU setting, to gain insight into the process of changing from a traditional model of care to FCC. The study was conducted in a 32-bed NICU in the US. Ten female nurses participated in this study where 5 were trained as intervenors to FCC, while the other 5 had not received this training. A qualitative research design was used and participants were interviewed using broad, open-ended questions with probes to elicit more descriptive detail.
Negative experiences of FCC were described by nurses who were not intervenors. Feelings of intimidation and loss of control were reported by nurses when parents told them what they would do and how they wanted the nurse to care for their baby. Even the intervenors recognized that parents with knowledge and permission to care for their infant can be intimidating. The negative experiences also reflected a loss of control by the nurses and their descriptions suggest they were asked to give up something very central to their professional identity. Some of the nurses felt intimidated with the parents trying to take over and wanted the parents to ask their permission to do things. Some nurses perceived a threat to the safety of the babies and had serious questions about their liability if the parents did something wrong. They seemed unable or unwilling to trust the judgement of a colleague that a mother knew what she was doing but needed to see for themselves. Such nurses’ identity is linked to their technical expertise while nurse intervenors, while maintaining their technically expert role, were able to work with families as expert coach, teacher and facilitator (Heerman & Wilson, 2000).

The nurses who were trained as intervenors in this study were self-selected since the research team asked for volunteers and was able to select all volunteers for training. This can be seen both as a strength and a limitation to the study. The nurse intervenors were already inclined to practice in this way and the study gave them permission and support for this model of care, which they approached with approval and enthusiasm. Thus, since the nurse intervenors in this study all wanted to move to FCC, the study does not necessarily reflect all the challenges of an entire unit’s transition to this model of care. Training in FCC is essential, but may not be sufficient for this transition since pre-existing and often unarticulated philosophies of
care may affect nurses’ experiences with FCC even after training. The small sample size and non-random sampling, limit the findings of this study and make generalizations of the results difficult.

Nonetheless, the results indicate that aspects of the NICU culture can inhibit or facilitate the move to FCC. Learning to share responsibility with families will require change in the NICU culture as well as in the nurses’ role identity. The role change required for the transition to partnering is that nurses relinquish the parenting role without feeling that their nursing identity is threatened but valuing and trusting the partnership with parents (Heerman & Wilson, 2000).

Fenwick, Barclay and Schmied (2001) in a grounded theory research study aimed to describe and explain, from the women’s perspectives, the experience of mothering in the NICU. Data were collected in 2 major Australian hospitals where 28 women were recruited into the study via nurseries with assistance from the nursery staff. Women were interviewed twice, one before their infant was discharged from the NICU and again some 8 to 12 weeks later at home.

A crucial finding of this study was the consequences of the interactions between nurses and mothers. Women perceived they gained access to their infants through nurses. Hence, the nurse-mother relationship had the potential to significantly affect how women perceived their mothering experience. The analysis of the women’s accounts identified two opposing sets of nursing interactions which women described as either facilitating or constraining their ability to take up their role as mothers. Nursing actions that facilitated a woman’s gaining intimate knowledge of her infant
and a determined place as her child's primary caregiver, paralleled closely with the principles of FCC espoused in the literature. Nurses who were facilitative acknowledged the unique interdependent nature of the maternal-infant relationship and enhanced opportunities for women to be with their infants in a meaningful way. Working with women and families in this way established trust, personal understanding and positive relationships. It was within these types of relationships that women described being greatly enabled to become connected to their infant (Fenwick et al, 2001).

Almost the opposite situation resulted when women were confronted by what they perceived to be behaviours that worked against or restricted their efforts to achieve a sense of physical closeness and intimacy with their infant. The grounded theory analysis revealed that inhibitive nursing actions reflected an authoritarian style of clinical practice that was primarily focused on protecting the infant. Employing inhibitive actions whether consciously or unconsciously, meant the nurse maintained her position as the expert, ensuring that she retained control over the infant and care routine and so leaving little room for the provision of care that is based on partnerships and equality. The most common reaction described by women as a result of inhibitive nursing behaviours was that of anger which was expressed by women in this study as related to feelings of frustration since they were denied participation in the infant's care (Fenwick et al, 2001).

Fenwick et al (2001) study, though limited by its small sample and exclusion of fathers from the NICU experience, complements the findings of Heerman and Wilson (2000) discussed earlier and provides valuable insight into the nurse-mother
relationship and its impact on the woman's ability to take up her mothering role. Fenwick et al (2001) suggest that examining the consequences of negative interactions is one way through which neonatal nurses can better understand the women's NICU experience. Similar findings have been found by the same authors, Fenwick et al (1999), in an ethnographic study similarly done in Australia where results indicate that activities in the SCBU remain very much task-oriented with nursing roles continuing to be medically and technically focused. The nurse remains the primary caregiver involved in actions related to the physical care of the baby with parents looking on even when the activities do not require high levels of professional expertise.

Wocial (1993) argues that family-centered care dictates that the relationship between staff and family is central and should be given the highest priority. According to Raines (1996) and Shellabarger and Thompson (1992), such a stance postulates that nursing care can only take place within a relationship that reflects trust, respect, openness and honesty. Only in a supportive collaborative relationship can the parents begin to feel empowered and ultimately become true partners with staff in the care of their infants (Rushton, 1990; Sweeney, 1997). Hence, parents are dependent on staff for encouragement and teaching as to what is appropriate and acceptable for them to do and when to do it, so it coincides with nursing care (Stewart, 1991). When parents are informed and educated about their infant, they can become knowledgeable and active partners in caring for their baby together with SCBU staff. Pearson and Anderson (2001) claim that parent education also improves communication with staff about the care of their baby and increases parents' success in caring for their infant.
Lau and Morse (1998) suggest that nurses are responsible for maintaining effective communication with parents and should be aware that parents of SCBU infants may experience high levels of anxiety where their ability to absorb information is often decreased by up to a third (Gennaro, York & Brooten, 1990). Consequently, information given to parents should be concise, clear and direct and it is important that nurses understand that they may have to repeat information perhaps several times, to ensure that parents understand (Taylor, 1986). The provision of brief printed information sheets designed in encouraging and supportive styles of language, may help the parents to understand and retain the information given (Lau & Morse, 1998). Parents need honest yet constructive advice about their child’s prognosis and such communication may be provided by scheduling pre-arranged discussions times with the parents and health care professionals with an opportunity for the parents to ask questions (Abel-Boone, Dokecki & Smith, 1989).

Bruns and McCollum (2002) carried out a descriptive study to examine the perspectives of mothers, nurses and neonatologists on the importance and implementation of NICU practices related to information exchange and relationships within the context of FCC. The PARTNERS questionnaire was developed and implemented, including both quantitative and qualitative items. The questionnaire consisted of Likert-type rating scale items, open-ended questions and a demographic data form. Two versions were developed, one for mothers and one for professionals. The content was the same, but phrasing and terminology were tailored to better capture the experience of the two groups. Six hospital sites were used in the study, two located in small cities and four were located in larger urban areas, all in the US. At the time of the study all units described themselves as providing FCC. Data
collection took place over twelve weeks. Two hundred and fifteen (215) questionnaires were distributed to professionals (25 neonatologists and 190 nurses) and 157 were mailed to mothers. The final sample included 141 professionals and 55 mother questionnaires (9% neonatologists, 63% nurses and 28% mothers).

Results relating to information exchange were grouped into one of two emerging themes; types of information exchanged in the NICU and the manner in which the information is presented. Information exchange related primarily to daily updates about infant progress and changes in medical status. All respondents voiced the need for easy-to-understand language and for multiple explanations of NICU equipments, medical procedures and test results. Mothers also stated that they wanted information to be honest and straightforward, even if it was bad news. Professionals concurred with this sentiment. Mothers also described how neonatologists and nurses often called them with progress reports and up-to-the minute information about changes in their infant’s medical status. These contacts were particularly salient for mothers who lived far from the NICU or had other family commitments that limited their visits to the unit. The more time they spent in the unit, the more familiar mothers became with the medical jargon, equipment, and procedures and the more inclined they were to ask questions of the staff. In response, professionals felt they provided information in a manner that matched parent needs and preferences. Yet, mothers sometimes described receiving conflicting information from different nurses or from a nurse and a neonatologist.

Two interrelated themes emerged in the area of relationships: the mother’s need for care and concern and how a relationship develops between mothers and professionals.
Underlying both themes was the need for trust, support and individualized attention matching the mothers' emotional and psychological state. Mothers described how individual professionals helped them feel comfortable in the SCBU environment and how they provided mothers with reassurance that their infant would overcome any medical issues. The mothers' responses indicated that they saw this reassurance as critical to developing a relationship with SCBU professionals. Neonatologists and nurses stressed the importance of supporting and having concern for the wellbeing of the parents while their infant is in the SCBU. The amount of contact in the unit appeared to be the main factor in developing parent-professional relationships and for this reason, relationships between mothers and nurses were more frequently developed than relationships between mothers and neonatologists.

Since this study (Bruns & McCollum, 2002) included 6 hospitals, it extends previous investigations of this type, which have typically been conducted in single sites or in multiple sites with only parent participants. In addition, the study expands on previous research by comparing responses across the different samples (mothers, neonatologists and nurses), although once again fathers are excluded from the study. Yet, results should be interpreted with caution since the participating hospitals varied from one another in size and population served, within each state. They were all located within a 100-mile radius of one another and so may not be representative of hospitals in other localities. The specific rating scale items appear to have content validity but additional analyses of the instrument are required for increased confidence in the results.
Nonetheless, this study (Bruns & McCollum, 2002) supports current guidelines for FCC, including the need for professional attention to the emotional component of parents' experience in the NICU. In this study, the likelihood that positive parent-professional relationships would develop, improved when mothers felt that professionals recognized their caregiving skills, provided information in ways they preferred and were sensitive to their emotional needs. Similarly, in various studies, parents have reported that their most important perceived needs in the NICU relate to information and support needs (Bass, 1991; Hurst, 2001; Ward, 2001; Bialoskurski et al, 2002). Different authors (Thurman, 1991; Abel-Boone et al, 1989) point out that providing support to parents while their infants are hospitalized in an NICU can reduce their stress and can positively affect the parent-infant relationship across time and that service delivery should be structured to provide families with the necessary support and to foster their independence and empowerment.

The perceptions of both mothers and fathers of critically ill infants of the helpfulness of support provided to them by health care professionals were identified in a study done by Miles, Carlson and Funk (1996). Two NICUs located one in the Midwest and one in the Southeast, USA participated in the study and interviews were done approximately one week after infant admission to the units (T1) and parents who were available were re-interviewed approximately one week after the initial interview (T2). At T1, 98 mothers and 60 fathers were interviewed; at T2 there were 51 mothers and 38 fathers. Of those, interviewed, 37 were mother-father dyads who were interviewed at both T1 and T2. Most infants were male (62%) and the mean gestational age was 31 weeks. The Illness Support Scale (ISS) was used to measure parents' perceptions of the helpfulness of support they received from health care
professionals by rating on a 5-point rating scale which included sixteen items. The ISS was adapted from the Family Support Scale (FSS) by Dunst, Trivette, Deavis and Cornwell (1988).

At both T1 and T2 parents perceived the helpfulness of support from nurses and neonatologists as very high. This suggests that nurses in NICUs have an important role in helping both mothers and fathers cope with their infant's hospitalization. Findings also suggest that fathers' perceptions of support change over time in a pattern different from that of the mothers. Of concern is the fact that the overall level of support fathers received dropped in the second week of the infant's hospitalization, whereas mothers’ support scores increased. This suggests that during the early days after admission when the mother is still recovering from delivery and may even be at a different hospital from the baby, the father may receive more support than the mother does as he plays a major role in communicating with the NICU healthcare team. However, during the subsequent weeks, when the mother is out of the hospital and often visiting the infant on a regular basis and when the father often must return to work and cannot visit as frequently, the mother may receive more support while the support to the father drops. Hence, the findings suggest that interventions are needed to support mothers during the early hospital period and to help fathers when they return to work.

Miles et al (1996) acknowledge that their study may be limited by the use of instrument since the scale measures helpfulness of support, however satisfaction with support is now considered a more robust measure of support. Furthermore, the instrument measures support broadly and does not include a rating of specific types
of support, such as informational, emotional, esteem or tangible assistance. Nonetheless, the support parents receive from health professionals, particularly nurses have been similarly found in other studies although these appeared as adjunct findings and not as the main study findings. In general nurses were perceived favourably by most mothers (Curran et al, 1997; Miles, Wilson & Docherty, 1999; Wereszczak et al, 1997), although some nurses were perceived as having bad attitudes (Miles et al, 1999), unapproachable, unhelpful and distant (Curran et al, 1997), while some acted too busy to talk to parents and provided little information (Wereszczak et al, 1997).

Miles et al (1999) in a retrospective descriptive study found that the support mothers received from nurses took the form of listening to their concerns, the provision of information about the child and caring about the mother as an individual. More importantly the nurses encouraged and helped the mothers to care for the sick infant thus increasing their self esteem and confidence. In Wereszczak et al’s (1997) study, mothers perceived nurses as being the ‘communication bridge’ between them and their baby by keeping parents informed of their baby’s condition and being the facilitators of communication between the physician and parents. Most mothers recalled the emotional support, positive attention, respect and encouragement they received from the nurses who demonstrated warm and concerned demeanors, instilled hope and treated each family as special.

The authors of these studies (Miles et al, 1996; Curran et al, 1997; Wereszczak et al, 1997; Miles et al, 1999) conclude that nurses in NICUs need to be aware of the importance of their support to parents and should develop their role in helping
families by identifying specific supportive interventions that are aimed at reducing parental stress, facilitating parental coping and improving the parental relationship with the sick infant (Miles et al, 1996). Such strategies are enhanced when caring relationships between nurses and parents are established and parents are treated as partners in the care of their infant (Wereszczak et al, 1997).

2.7 Conclusion

Studies discussed in this literature review may be limited by the small sample sizes (Curran et al, 1997; Wereszczak et al, 1997; Heerman & Wilson, 2000) and non-random sampling (Dobbins et al, 1994; Heerman & Wilson, 2000), thus limiting the generalization of the findings. Studies also lack consideration of issues such as the 'halo effect' (Heerman & Wilson, 2000; Fenwick et al, 2001), the effect of nurses' attitudes (Dobbins et al, 1994; Franck & Spencer, 2003), the severity of the illness (Dobbins et al, 1994; Franck & Spencer, 2003) and researcher or interviewer bias (Wereszczak et al, 1997; Heerman & Wilson, 2000; Fenwick et al, 2001). Interpretation of the results is also limited through the common use of fixed responses questionnaires and Likert-type scales (McHaffie, 1992; Miles et al, 1996; Bruns & McCollum, 2002) as it is not possible to ascertain the reasons for individual responses. Most research with families in the SCBU has involved mothers; seldom are fathers or other members included (Wereszczak et al, 1997; Fenwick et al, 2001; Bruns & McCollum, 2002; Nystrom & Axelsson, 2002). Specific study findings are limited to the respondents who participated and perhaps others who are similarly situated. Further research is needed to identify particular differences in different
populations of families experiencing neonatal intensive care, since culture and health care systems differ across settings.

Studies which have sought to understand the lived experience of parent participation from a more phenomenological perspective are largely absent and Darbyshire (1993) argues that if neonatal nursing is to continue to advocate and develop a philosophy of care based upon mutuality and partnership, then nurses need a deeper understanding of the nature of parents’ experiences and how these relate to their own nursing practices. In this way the relational and contextual aspects of lived experiences and relationships may be uncovered and the voices of the research participants may be heard rather than assumed or ignored.
CHAPTER 3

METHODOLOGY
3.1 Research question

What are parents’ experiences of family-centered care in the Special Care Baby Unit (SCBU)?

3.2 Aim of the study

This study aimed to explore parents’ experiences of their participation and involvement in the care of their newborn in the local SCBU.

3.3 Operational definitions

For the purpose of this study operational definitions were clearly established (Cormack, 1996). Hence, the definition of ‘parents’ was taken to refer to the biological mother and father of the newborn child hospitalized in the SCBU. ‘Experience’ referred to what the parents have gone through during their child’s hospitalization in the ‘SCBU’, which is a unit of a hospital designed with special equipment and specializes in the care of ill or premature newborn infants. For ‘family-centered care’ (FCC), the definition put forward by Smith et al (2002) was used. Accordingly, FCC referred to ‘the professional support of the child and family through a process of involvement, participation and partnership, underpinned by empowerment and negotiation’ (Smith et al, 2002 p.22).
3.4 **The research design**

This study adopted a qualitative approach using the hermeneutic phenomenological method. Phenomenology is an inductive, descriptive research method, which considers all that is available in the experience under study, both subjective and objective and strives to understand the total meaning that the experience has for the participants (Taylor, 1993). Such a research design has been aided by the nature of the research question and because the topic needed to be explored (Creswell, 1998).

The literature search revealed that little qualitative work has been done in studying family-centered care and none that explored the parents' experiences was encountered. Therefore, this research intended to produce the depth of information sought and to present a more detailed view of the topic which potentially contributes to a wider knowledge base in this area of study (Creswell, 1998). Phenomenology provided a method which focused on the parents' experiences of the care they received, and which provides insights into how the delivery of care can be improved (Taylor, 1993; Jasper, 1994).

3.4.1 **Philosophical underpinnings of phenomenology**

Edmund Husserl, is considered the founding father of phenomenology (Burke, 1992; Jasper, 1994), which became to mean the study of phenomena as they appear through the consciousness. Central to Husserl's approach was the fundamental recognition of experience as the ultimate ground and meaning of knowledge (Koch, 1995). Although Husserl introduced the concept of life-world or lived experience, his
method focuses on a description of the lived world that conceptualizes people as detached subjects existing in a world of objects (Koch, 1995). A researcher adopting Husserlian phenomenology brackets his own prior beliefs, values and knowledge and stands outside the research process, assuming a distance and objectivity at all stages of the research (Lowes & Prowse, 2001).

Husserl’s student, Heidegger, sought to answer the question of the meaning of being and seeks to understand the essence of an individual’s being—(the inner consciousness), acknowledging the uniqueness of individual experiences whilst searching for commonalities of meaning (Koch, 1996). Heideggerian phenomenology is also referred to as interpretive or hermeneutic phenomenology. Heidegger rejected the notion that we are observing subjects separated from the world of objects, about which we try to gain knowledge, but rather we are beings inseparable from an already existing world (Burke, 1999). Heidegger called our basic activity ‘being-in-the-world’ as we are constantly adapting to our situation. In hermeneutic research, the researcher is an active participant in the interpretive process rather than a passive recipient of knowledge (Walters, 1995). The presuppositions the researcher brings to the research experience are examined and made explicit rather then suspended (Burke, 1999). Data generated by the participants is fused with the experience of the researcher and placed in context. This co-constitution of data is the main distinguishing characteristic from Husserl’s phenomenology (Koch, 1996).

My main preconceptions relevant to this study include the fact that I am a female and a midwife which makes my concern for family-centered care more pronounced. I am
also married but have no children of my own yet, which may make my understanding of such parents' experiences more difficult although my two years experience of working in the NICU helps me understand such situations more. I also decided not to care for the babies whose parents were chosen to participate in the study so as not to influence the care given and bias the study. Another preconception I had prior to the commencement of this study was that in the local SCBU certain characteristics of family-centered care are being practised but the extent to which such care is experienced by parents is unclear. However, parents' experiences would help reveal such practices and would aid in the formulation of a family-centered care policy in the local setting.

I acknowledged that Heidegger's hermeneutic phenomenology was the more appropriate method to use to answer the research question in this study, particularly because of my own experience of working in the NICU, with the families of sick newborns thus having prior preconceptions and knowledge of the study phenomena from direct experience prior to the commencement of this study. Bracketing or complete reduction of such experience, and preconceptions, as suggested by Husserl, would have been difficult to achieve, thus making Heidegger's method the better choice. Since I had an inherent interest in the study phenomena before undertaking literature searches, then a literature review was carried out prior to the commencement of the study, which is accepted when using Heideggerian phenomenology, since the researcher's preconceptions are integral to the entire research process (Lowes & Prowse, 2001). The literature review helped to generate the questions used in the semi-structured interview schedule adopted for this study.
3.5 **Inclusion criteria and sampling**

Participants recruited to the study had common characteristics, in that they were Maltese parents whose babies were born at 37 weeks gestation or more and were admitted to the local SCBU with minor problems, which included; hypoglycaemia, mild respiratory distress or dehydration. These criteria were chosen so that the study would be particular to the Maltese culture, and hence the reason why all participants were required to be Maltese. The fact that the babies were born at 37 weeks gestation or more, indicated that they were all beyond prematurity and this also has implications on the length of hospitalization in the SCBU together with that of being admitted with minor problems, where in none of the cases was very intensive treatment required. Purposive sampling, a non-probability sampling method is quick and provides an opportunity to select participants with the characteristics of interest and is considered appropriate for hermeneutic studies (Polit, Beck & Hungler, 2001). I selected the study participants on the basis of personal judgement about which ones would be most representative and productive in accordance with the aim of the study (Polit et al, 2001). Since I work in the same environment from where the participants were recruited for the study, I was more likely to determine which parents would provide the required data for the study. All parents approached agreed to participate in the study. To avoid researcher bias in the care provided, I did not care for the newborn infant, whose parents were chosen to participate in the study.

One couple (mother-father dyad) was included in a pilot study and since no substantial changes were done in the interview schedule to use for the main study, the
findings of this couple were included with the data produced from another five couples who participated in the main study. The sample size was determined on the basis of informational needs and for the aim of the study to be achieved (Morse, 1994). The sample size also reflected the need to achieve a balance between the time available to work on the study, the length of each interview and an appreciation of the depth and associated time needed to undertake transcription and analysis (Smith & Osborn, 2004; Whitehead, 2004). According to Whitehead (2004), such a sample size is considered appropriate in hermeneutic studies.

Theoretical saturation is not sought in hermeneutic studies as the temporality of truth is recognized (Crist & Tanner, 2003). Drew (1989) says that in phenomenological research the data produced from memory and recall when recounting of past experience, are not collected with the intention of generalizing to a larger population but rather to enhance the composite human phenomena with which we understand lived experience. Accordingly, it was not intended that the findings of this qualitative research will be generalisable, but to apply only to the specific population under investigation. In purposive sampling my judgement and knowledge of the population was crucial and there is potential for selection bias.

3.6 Data collection

Audio-taped semi-structured interviews were the method of data collection used which provided a situation where the participants' descriptions could be explored, illuminated and gently probed (Smith & Osborn, 2004; Wimpenny & Gass, 2000).
Interviews were conducted following the infants' discharge home from the SCBU to avoid the halo effect which often occurs when participants are interviewed during their hospital experience, when people are generally reluctant to criticize nursing staff, as they feel that their comments might somehow prejudice future care (Neill, 1996; Polit et al., 2001). One semi-structured interview schedule was developed and repeated three times with each couple (Seidman, 1991). In the first encounter the participants developed their life experience, in the second parents were asked to clarify and elaborate on specific issues that appeared important in the first encounter and also provide any new lines of inquiry if relevant. The third encounter focused on the participants' verification of the data and interpretations derived from the previous interviews and also asked for anything else they would have liked to add relevant to their experience. In the second and third encounters parents expanded more on the responses given in the first encounter but no new findings or new themes emerged which indicated data saturation.

On the first encounter prior to commencing, demographic data was obtained by filling a pre-prepared form (appendix D). The first interview was done 2 – 4 weeks following discharge, the second 5 – 7 weeks following discharge and the third interview was done 8 – 10 weeks after discharge. The timings of such interviews were chosen so that parents' recall bias would be avoided as much as possible, yet allowing them enough time to settle down at home. The time gap chosen between interviews was considered appropriate to give the parents time for reflection on the previous interviews. The timings chosen were appropriate as to the availability of both parents and the researcher. Making arrangements for a suitable time which for
all three parties concerned was not always easy, particularly due to work and family commitments.

Oppenheim (1992) argues that the participants' motivation to the study determines both response rate and the quality of the responses which has implications for the validity of the study. Thus, interviewing was held at the participants' convenience and in the comfort of their homes. To encourage as much participation amongst parents as possible (Crist & Tanner, 2003), parents were asked which was their preferred language to use during the interviews, Maltese or English. All participants chose to use the Maltese language during the interviews, although some used both Maltese and English interchangeably during their discussions but Maltese was the predominant language used. The initial interviews for each couple were the longest and lasted about 30 minutes to one hour each, while subsequent interviews lasted a maximum of 20 minutes.

A semi-structured interview schedule prepared in both languages, was developed for the purpose of this study (appendix E). Advice from my supervisor was sought and amendments were made until it was agreed that the interview schedule would elicit the desired data. Unlike unstructured interviews, a semi-structured interview helped to guide the participants in answering the main research question and so ensured that all participants maintained a focus on their experience and covered the required aim of the study. During the interviews my role was to guide the interview and keep the participants to the topic (Field & Morse, 1985). The schedule remained constant throughout the interview and contained standard probes. Yet, there were no
consistent wording or ordering of questions and I was free to follow the course of any particular interaction provided that the required information was collected.

As I became more experienced in facilitating parents’ interviews, less reliance was placed on the schedule and the flow of conversation between the parents and myself became more natural. This allowed me to follow issues which were not included in the schedule but which appeared relevant to the research. Semi-structured interviews allowed the opportunity for expansion of replies and the consistency of areas covered aided analysis (Whitehead, 2004). I was aware that the manner in which participants are approached and questioned in an interview influences the type of response participants are willing to volunteer, and the amount of discussion they are willing to enter into. Hence, it was important to adopt an open and accepting interviewing style which permitted participants to voice their genuine views, opinions and feelings without constraint (Hardey & Mulhall, 1994).

Literature (Crist & Tanner, 2003; Whitehead, 2004) suggests that throughout the interviews, the researcher should take fieldnotes, which includes observations to supplement the taped interviews, namely; a written account of the things the researcher heard, saw, experienced and thought in the course of collecting or reflecting on the data. Non-verbal communication, such as vocal intonations, physical expressions and gestures which are not audible in the recorded interviews, should also be noted and later incorporated into the transcribed narrative texts and eventually analysed. However, I thought that the taking down of such fieldnotes during the course of the interviews, could have caused distraction during interviews both for participants, as they narrate their experience to someone who is writing and
not giving them full attention and for me, who would not be focusing on what is being said by the participants. For these reasons, fieldnotes were written down, as soon as I left the participants' home, in my own car.

3.7 **Rigour**

Rigour relates to the overall planning and implementation of the research design and concerns whether a study has been carried out in a logical, systematic way or not. The interdependence of qualitative research demands that the question matches the method, which in turn matches the data and the analytic procedures. Rigour is described as 'the striving for excellence in research through the use of discipline, scrupulous adherence to detail and strict accuracy' (Burns & Grove 1997, p. 793). When considering the rigour (or trustworthiness) of a qualitative study one needs to consider credibility, transferability, confirmability and auditability (Lincoln & Guba, 1985).

A measure of the credibility (comparable with validity) of the data can be obtained by the degree of confidence the researcher inspires in others (Lincoln & Guba, 1985; Carter & Porter, 2000). Prolonged engagement where sufficient time was invested in data collection activities to have an in-depth understanding of the language and views of the participants under study and to test for misinformation, was one way how I could assure the reader of the credibility of the study. Another very important technique is using verification (or member-checking) which referred to the process of returning with the interview transcripts to participants who were asked to check the
accuracy of interpretation (Morse & Field, 1995). This was the main focus of the third encounter where credibility related to whether the interpretations were recognized to be true by those who had gone through the experience (Oiler, 1982).

Another aspect of credibility discussed by Patton (1990) is researcher credibility, the faith that can be put in the researcher. In Heideggerian phenomenological research, the researcher’s background; qualifications, experience, prior knowledge and preconceptions of study phenomena are interconnected with the research influencing responses to participants, data generation and analysis (Rodgers & Cowles, 1993; Polit et al., 2001). Consequently, the credibility of the reported findings rests not only on the procedures used to generate and analyze findings but also on the self-awareness of the researcher throughout the research process. Hence, in this study I acknowledged and documented such information, in the relevant sections when writing up this dissertation thus making explicit my influence upon the research to the scrutiny of readers, who can make their own judgements about the authenticity and persuasiveness of the findings. This is referred to as reflexivity which in the absence of statistical tests for validity and reliability is crucial to qualitative research if it is to be persuasive (Cormack, 1996).

Transferability (comparable with generalizability) relates to the extent to which we can see similarities in the findings that may relate to other similar settings (Lincoln & Guba, 1985). This required that I provide details about the setting and the events taking place and such descriptions allow the readers to assess whether the people and events could be applicable elsewhere. This is sometimes referred to as applicability or fittingness. Fittingness of the study was also increased by seeking out participants
who not only had experienced the phenomenon under study but also were able to articulate their experiences.

Another aspect of rigour is confirmability (comparable with objectivity or neutrality) which is concerned with establishing that data and interpretations of the findings are not inventions of the researcher's imagination, but are clearly derived from the data (Tobin & Begley, 2004). Verifications of the interpretations with the participants in the third encounter and using verbatim extracts from the participants own discussions help to aid confirmability of the findings. I also kept a record of all documentation of the entire research process, including the recorded interviews, should these become necessary by others.

For auditability I provided a clear account of the research process so that readers can judge the dependability (comparable with reliability) of this qualitative study. Clearly describing each stage of the research process, explaining and justifying what was done and why, increases auditability (Lincoln & Guba, 1985). The pilot interview done also increased reliability as I developed interviewing skills prior to the main study. Reliability was also addressed in terms of equipment employed in the interviews. Using tape recording to record all interviews, helped increase reliability as this provided an accurate account of what had been said (Appleton, 1995). Audio-taping provided a detailed insight into the performance of both the respondent and the researcher. Access to the interactions between respondent and me, as in intonations and pauses, help validate the accuracy and completeness of the information collected. Audio-taping also reduced the potential for researcher error by, for instance,
recording data incorrectly or logging an answer to a question that was not asked (Barriball & While, 1994).

3.8 Ethical considerations

Initially the proposed title for this study was approved by the MSc Health Science (Nursing/Midwifery) Board of Studies. In order to gain access to the research site to recruit parents to participate in the study, permission from the Chairman of Paediatrics was gained (appendix B). Permission was also sought and approved from the Institute of Health Care Research Ethics Board and the University of Malta.

Potential participants were informed about the purpose and nature of the study, both verbally and in writing, when their child was approaching discharge from the SCBU. I provided potential participants with a covering letter, in both Maltese and English (appendix C), where I explained who I was and the capacity in which I was writing. An explanation of the study and its aim in broad terms was provided. I also explained why the persons receiving the letter had been included as potential participants for the study and encouraged them to take part in the research. Potential participants were informed about the nature of the interviews, namely that three interviews will be held at times convenient to them and in their own home, so addressing the participants’ privacy and comfort. In addition, they were informed that each interview would take a maximum of one hour and would be tape-recorded.
They were advised that their participation was voluntary and that they had a right to refuse to take part or withdraw from the study at anytime (Polit et al, 2001). Written consent from all those who chose to participate in the study was obtained in writing prior to commencing the first interview. Informed consent is considered to be one of the means by which participants’ rights are protected (Smith, 1992). Since data collection was done through face-to-face interviews, total anonymity of the participants was not possible and so I ensured that confidentiality would be maintained and assured participants that all information they provided would be kept confidential and used only for the purpose of the study. When analyzing the data, personal details, which might identify the participants, were altered and pseudo names were used. Participants were also informed that following submission of this research project, data from tapes would be destroyed and thus adhering to data protection regulations (Smith, 1992).

3.9 **Pilot study**

Unforeseen problems could arise in the course of a research project (Polit et al, 2001) and a pilot study, which is a small-scale version of the main study, is designed to obtain the necessary information about what needs to be modified and also assess whether the main study is feasible to be carried out (Bailey, 1991). Polit et al (2001) suggest that the participants taking part in the pilot study should be chosen from the same population as the participants for the main study. In this way, they claim that participants for the pilot study possess similar characteristics as the individuals
composing the main study. In fact, for the pilot study I chose a couple who possessed the same inclusion criteria set for participants in the main study.

The principle focus of this pilot study was the assessment of the adequacy of the data collection method. Interview schedule was therefore pre-tested to establish whether the respondents understood the questions and probes and revealed that these were clear and easily understood. This indicated that no substantive changes were necessary and the conceptual nature of the interview schedule was not altered. The pilot test indicated that the semi-structured interview schedule would elicit the desired data (Oppenheim, 1992).

### 3.10 Data analysis

Data for this study was analysed using interpretative phenomenological analysis (IPA), whose aim is to explore in detail the participants’ view of the topic under investigation. This approach is phenomenological since it is concerned with an individual’s personal account of an event as opposed to an attempt to produce an objective statement of the event itself (Smith, Jarman & Osborn, 1999). IPA also recognizes that the research exercise is a dynamic process where one is trying to get close to the participant’s personal world, to take an ‘insider’s perspective’ but one cannot do this directly or completely. Access depends on, and is complicated by, the researcher’s own conceptions and indeed these are required in order to make sense of the other person’s world through a process of interpretative activity. Hence, the term
interpretative phenomenological analysis is used to signal these two facets of the approach (Smith et al, 1999).

Audio-taped interviews with participants were transcribed verbatim, since there was no way I could document everything that was being said in the interview in sufficient detail to allow a thorough analysis afterwards (Smith & Osborn, 2004). Since the Maltese language was the predominant language used during the interviews, transcriptions were left in Maltese. The first transcript was read a number of times, and on the left side of the margin I took note of anything which interested me. The transcript was read and re-read closely in order to become familiar with the account, since each reading was likely to produce new insights. At this stage, some of my comments included attempts at summarizing, associations or connections that came to mind, or preliminary interpretations. I went through the whole interview making preliminary notes on the left margin, then the right margin was used to document emerging theme titles, that is, using key words to include the essential quality of what was being found in the text. At this preliminary stage the key words were not definitive but enabled me to articulate something about the concept identified. Such emerging themes were initially done in Maltese and then translated to English.

As I moved through each transcript, some of the notes reflected connections with previous sections of the interview, referring to similarities and differences in what the participant was saying. At this stage all of the transcript was treated as potential data and no attempt was made to omit or select particular passages for special attention. On a separate sheet the emerging themes were listed and connections between them were sought. It was noted that some of the themes clustered together and some were
regarded as superordinate concepts (Smith et al, 1999). As new clusterings of themes emerged, the transcript was re-checked to make sure that the connections work for the primary source material, that is what the participants actually said. This form of analysis involved a close interaction between the researcher and the text, attempting to understand what the person is saying but, as part of the process, drawing on the researcher's interpretative resources.

The next stage was to produce a master list or table of the themes, ordered coherently (Smith et al, 1999). The process outlined above identified a number of major themes and sub-themes in some instances, which seemed to capture most strongly the respondents' experiences on this particular topic of FCC in the SCBU. It was ensured that each theme was represented in the verbatim transcript, and where appropriate, the master list also identified sub-themes which related to some of the main themes. For each theme I indicated where in the transcript instances of it can be found by using verbatim extracts, first as said by the participants in the Maltese language then as translated into English, indicating the page and line number where in the transcript these could be found. Some of the themes were governed by and followed closely the questions on the interview schedule, but others were completely new as some respondents tackled the subject in a different way from that anticipated by the researcher (Smith & Osborn, 2004). It was important to remember at this stage that analysis is a cyclical process, and it was necessary to go through the stages a number of times, dropping a certain theme when a more useful one emerged.

When the first interview was analysed I moved on to analyse the rest of the interviews. With each interview transcript I started anew, going through the stages
outlined above and producing a master list for each interview. The master lists for each interview were then read together and a consolidated list of master themes for the group was produced. Since the process is cyclical, when new themes emerged in subsequent interviews, they were tested against earlier transcripts. Themes were not selected purely on the basis of their prevalence within the data. Other factors, including the richness of the particular passages which highlighted the themes, and how the theme helped illuminate other aspects of the account, were also taken into account. The writing up of the results used the table of themes as the basis of an account of the participants' responses which took the form of an argument interspersed with verbatim quotations from the transcripts to illustrate responses on relevant themes and sub-themes.

The next chapter will explore and discuss the findings of this study focusing on the themes which emerged in the data analysis.
CHAPTER 4

FINDINGS AND DISCUSSION
4.1 Introduction and background

The aim of this study was to explore parents' experiences of their participation and involvement in the care of their newborn in the local SCBU. Data was obtained by using a semi-structured interview schedule which was repeated three times with each of the six couples who participated in this study. As set by the inclusion criteria for this study, all parents were Maltese thus maintaining cultural issues constant as much as possible. The gestation at time of delivery of the babies hospitalized in the SCBU ranged between 37 and 40 weeks. The findings did not differ in aspects related to the infants' gestational age possibly because all infants were considered to be term infants and there was only a narrow difference between their gestational ages. Two aspects of the demographic data which influenced the results included; the mode of delivery and the timing after birth when the infant was admitted to the SCBU. From the six couples interviewed five had a cesarean section and one had a normal vaginal delivery. In three of the cases, the baby was admitted to the SCBU immediately after birth while in the other three the baby's admission was either after a few hours or the next day following birth. As will be explored in this chapter, the mode of delivery and the timing after birth when the infant was admitted to the SCBU, had influences on the parents' experiences of their infants' hospitalization in SCBU.

The inclusion criteria set for this study stipulated that the parents of infants admitted to SCBU with minor problems would be eligible to participate. This was set so that there would not be drastic variations in the intensiveness of the treatment required. The reasons for SCBU admission in this study included; hypoglycaemia, mild
respiratory distress or dehydration. No differences as such were noted in the parents’ experiences relating to the child’s condition, possibly because all are considered more or less to be of similar severity.

On the other hand, having had a previous experience of SCBU hospitalization with another child of their own had influences on the parents’ experiences. Only one couple had such an experience, whose first child was admitted with the same condition as the second child. Having had such a previous experience has had very evident influences on the parents’ second experience of SCBU hospitalization which was not noted in that of the other parents. These experiences will be explored in more detail shortly.

Parents’ experiences were also noted to be influenced by whether they had other siblings in their family. This issue was noted to be particularly relevant when considering the issue of visitation by siblings in SCBU. In this study three couples had other children; two of these had another child while the other couple had two other children. Since this study included interviews with both parents of each infant, one could notice both similarities and differences between the mothers’ and the fathers’ experiences in SCBU which are relevant to this study.

The influences of such demographic data on the findings of this study will be explored and discussed in detail in the following section. Findings will also be discussed in light of other research findings found in previous studies and in context of the family systems theory, which was the theoretic framework chosen for this study.

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An interpretative phenomenological analysis of the transcribed interviews was conducted and six major themes emerged. These included; 'reactions to SCBU', 'caring for baby', 'barriers to child care', 'bonding with baby', 'staff behaviours and attitudes' and 'visiting the baby'. Where appropriate sub-themes relating to these major themes were also identified. The themes and sub-themes which emerged from the analysis are presented in the table below and will then be discussed in due course. Verbatim quotations relevant to the themes and sub-themes being discussed will be presented, however, due to word limit not all such relevant quotes will be included in this section but further quotes will be included in Appendix F.

| 1. Reactions to SCBU |
| 2. Caring for baby |
| 3. Barriers to child care |
| 4. Bonding with baby |
| 5. Staff behaviours and attitudes |
|   • Need for information |
|   • Need to care for baby |
| 6. Visiting the baby |
|   • Parents' visiting |
|   • Visiting by siblings |
|   • Visiting by relatives |

Table 4.1 Master list of themes and sub-themes
4.2 Themes

4.2.1 Reactions to SCBU

On reflecting back on their experience in SCBU, it became evident that all parents experienced various reactions which included both feelings and thoughts they had during their child’s hospitalization. In viewing the family as a system as proposed by the family systems theory, it is considered important to acknowledge reactions which are known to be unique to each family member, the mother and father in this case, in order to be able to focus care that supports the family unit as a whole and focusing on different family members (Syndnor-Greenberg & Dokken 2000; Tosh 2001). I was impressed how vividly all parents recalled their initial reactions when told that their newborn required care in SCBU together with subsequent reactions they experienced throughout the baby’s hospitalization. The look in their eyes was also noted to be a reflection of such reactions. The most common initial reaction, especially for mothers, was that of shock, particularly due to uncertainty.

“Dak il-hin hadt xokk……. vera kont hadtha bi kbira.” (Jane Borg, int 1, line 6)

“At that moment I was shocked……I really took it badly.”

“Dak il-hin, xokk ghax ma kontx naf ghaliex…….” (Ruth Spiteri, int 4, line 3)

“At that time, shock because I did not know why…….”
One mother recalled that initially her reactions were unclear but once the news started to sink in, she was afraid. The words SCBU made her afraid and avoided using these words.

"Ma bdejtnahsebf'xejnprattikament, qiesnintrajt go dinjaghaliija, dik hil-
kelma.......imbaghadheqqSCBUil-kelmdigatma semmejtha,
ankindihidulifejnahuil-baby, kontnghidilhomfuqlil-kelmaSCBUqat
m'uzajtha." (Sue Vella, int 2, line 24).

"I was not thinking about anything practically, it was like I was in a world of my
own, that's the word......then the word SCBU already frightens you and I never
mentioned it, even when asked where the baby was, I used to say upstairs and I
never used the word SCBU."

Another mother said that initially she did not take the news so badly because she did
not know what SCBU meant but once she was told she was worried.

".......ghall-ewwelmahadtiexdaqshekbikbira, makontx naf x'jiżifieri SCBU u
ghaliex. MetaqallisspeciSCBUBhalITUtal-kbar, immataż-żghar, hemmhekk
iva inkwetajtruhi...." (Julie Muscat, int 6, line 6)

"......at first I did not take it so badly, I did not know what SCBU meant and
why. When told SCBU was like ITU for adults, but for the young, then yes I got
worried....."

I noted that those mothers whose baby was admitted to SCBU immediately after a
caesarean delivery, had worse reactions to the child's admission particularly during
the first twenty-four hours as due to the cesarean delivery they were not in contact with the baby. Feeling helpless, fearing the worst for their baby and being worried were common reactions to such mothers, particularly since they did not really know what was happening and what was wrong with the child.

“...jien l-iktar li dejqetni li minhabba ċ-česarja l-ewwel 24 hours ma tistax tqum, allura dik il-haġa li qieghda hemm qiesni ġo habs locked, ma nistax nara x’inhu jįği, dik dejqitni wisq. L-iktar li nkwetaji l-ewwel 24 hours, nahseb hux qed jiebu nifs sew jew li ghandu xi haga hazina, il-hin kollu nahseb. You do think the worst, li allabares qatt imut, jiena il-hin kollu nahseb u ma bdejt nemmen lil badd.” (Sue Vella int 2, line 20)

“...what I did not like was that because of the cesarean the first 24 hours you cannot get up so that thing of being there like locked in prison, I cannot see what is happening, I really did not like that. I was worried the most in the first 24 hours, thinking whether he is breathing or that he has something wrong, thinking all the time. You do think the worst, that godforbid he dies, I used to think all the time and I was not believing anyone.”

“...dak il-hin ma tkunx tista’ tqum mis-sodda, l-ewwel ġurnata tinkwieta ghax ma tkunx taf’x qed jigri mit-tifla.” (Ruth Spiteri int 4, line 11)

“...at that time you cannot get out of bed, the first day I worried because I did not know what was happening to my daughter.”

In essence, such negative reactions expressed by the mothers in this study, compare well with those found by Curran et al (1997), who in their study explored the
psychoemotional problems of parents of NICU infants. However, it should be noted that the in-depth data produced in this study, may be difficult to compare to the findings obtained by Curran et al (1997) who used questionnaires to collect their data.

The fathers in this study also expressed how they had reacted to their child’s admission to SCBU. I may not have realized prior to this study that fathers could be so much affected by this event, possible because of the lack of such fathers’ experiences in the literature. Listening to them during the interviews and noting their non-verbals and mannerisms whilst they talked surely indicated that fathers too are deeply influenced by such an experience. Being shocked, worried and feeling helpless were common reactions amongst the fathers interviewed, particularly since their child’s admission to SCBU was an unexpected event.

"...tebodha shock minghajr ma trid, is-soltu jidhlu jixtru llum u johorgu wara jumejn, imma taghmel 18 days hemmhekk fihom." (James Mifsud, int 5, pg. 11 line 25)

"...you take it as a shock without wanting to, usually they go in deliver today and are discharged after two days, but spending eighteen days there is no joke."

"...bla dubju ta’ xejn tieṭu shock, il-fatt li jghidulek li tielgha l-SCBU, li hija l-ITU taż-żgbar, heqq bla dubju hija shock, ċżjed u ċżjed meta dan ahna huwa t- tieını baby, fejn l-ewwel baby kien hlas normali u ma kellu bżonn l-ebda assistenza, allura minghajr ma trid mill-ewwel tghid x’ghandu." (Brian Muscat, int 6, pg. 2 line 17)
“...without any doubt you get a shock, the fact that they tell that you he needs to be in SCBU, which is an ITU for the young, it is a shock without doubt, more and more so when this is our second baby, where the first baby was a normal delivery and needed no assistance, so without wanting to you ask what is wrong.”

“...dak il-hin il-ġenituri jkunu vulnerabli nista nassigurak, I mean iebes kemm tkun iebes, min ikun jaf ihobb dak il-hin ihossu vulnerabli.” (Brian Muscat, int 6 pg. 10 line 9)

“...at that time the parents are vulnerable I can assure you, I mean strong as much as you are, those who know how to love feel vulnerable at that time.”

Another two fathers added that the situation was uncomfortable, they acted indifferently and kept calm to be able to support their wives.

“...vera hassejini antipatiku imma mbaghad fl-ahhar mill-ahhar li jrid isir isir fis-sens anke biex naghmel kuragg lill-mara jiġifieri hekk qiesni kont indifferenti ghamilt ta’ bir-ruhi li jien indifferenti.” (Anton Spiteri, int 4 pg. 1 line 14)

“... I really felt uncomfortable but at the end what has to happen happens in the sense that even to support my wife I mean I was indifferent I acted indifferently.”

“...jien bqajt kalm....trid tissaportja lilha wkoll.” (James Mifsud, int 5 pg. 12 line 26)

“....I remained calm...you have to support her too.”
Unfortunately such findings cannot be compared to findings in other studies explored the literature review, because fathers are largely excluded in such research which seems to be a major limitation in the existing literature. In Curran et al (1997), although both parents were included in their study, yet findings were not attributed to gender and so the actual fathers’ responses are not clear and cannot really be compared to the present study. Nonetheless, it became evident in this study that fathers too react to the child’s SCBU hospitalization in some ways which are similar and others which differ to the mothers’ reactions and findings reflect what is repeatedly emphasized in the literature, that the hospitalization of an infant in SCBU is a stressful experience for the family (Fenwick et al, 2003; Bialoskurski et al, 2002; Saunders et al, 2003). It is thus often argued that understanding both mothers’ and fathers’ reactions is important in providing family-centered care.

It seems that since most of the fathers accompanied the baby to SCBU and could see the child, where he was and knowing what was being done to him, they soon felt better. This may be considered an important element of family-centered care which is currently practised locally, where the father is included in the initial stages of the baby’s care and which has been found to help reassure the fathers.

“...jiena tlajt dak il-hin u apprezzajtha hafa li I was allowed to go to the SCBU with the baby, fil-verita nahseb li taghmel tajeb hafa ghafl-żentur ghax iħossu komdu ħżejed, juriq li m’hemmx dik l-urgenza gravi ....il-fatt li jhalluk titla bil-kwiet hi ta’ konfort.” (Brian Muscat int 6 pg. 3 line 15)

“...I went up at that time and I appreciated a lot that I was allowed to go to the SCBU with the baby, in reality I think that is really good for the parent because
he feels more comfortable, it shows that there is not that critically
emergency...the fact that they let you go up quietly is comforting.”

On entering the SCBU environment for the first time and seeing their baby, mothers
were frightened and worried particularly by the equipment used, not knowing what it
was there for. Such reactions pertaining to the unfamiliar SCBU environment,
technology and infant’s appearance have similarly been highlighted by other authors
in this area of study, namely Thurman (1991), Wereszczak et al (1997), Pearson and
Anderson (2000) and Spencer and Edwards (2001), which clearly indicating the
impact of such a high-tech environment on the parents’ reactions to SCBU.

“.... inkwetajt meta rajitha b’hafna affairijiet, magni ma tafx x’inhuma. L-ewwel
darba li tlajt dawn l-affarrijiet hassduni.” (Diane Mifsud int 5 pg. 1 line12)

“....I was worried when I saw her with a lot of things, equipment not knowing
what it is for. The first time I went up these things startled me.”

“....kif tlajt hadt qata’ kbira ghax jien SCBU tigix tghidli x’kien fih ghax qatt
ma kont rajtu, meta tarah l-ewwel darba tibda tarah b’dawk il-wires, dawk il-
pajpijiet, tibda tghid x’ghandu.... L-ewwel daqqa t’ghajn qiesha tahsdek...u
tiehu qata’ ghax tibda tghid metla ghandu xi haga li m’hiexnormali, jiena hekk
hadtha, hekk hassejmi.... U ghaimilt id-dwejjaq meta rajtu.” (Julie Muscat int
6 pg 21 line 2)

“...when I went up I got a big fright because I did not know what SCBU was
because I had never seen it, when you see him for the first time with those wires
and pipes, you start asking what is wrong with him....this first glimpse startles
you...and you get a fright because you start saying he has something which is not normal, that is how I took it, that it how I felt...and I became sad when I saw him.’’

For the couple who had a previous similar experience in SCBU, their reactions to their second child’s admission to the unit were completely different from those of the other parents. They expressed that they had been prepared during pregnancy that their second child would probably have the same condition as their first child and similarly requiring care in SCBU. They recalled that it was not a shock for them since they were prepared and aware of the condition and its progression. The couple compared these reactions to their first experience which similar to the other parents was initially experienced by shock. Such findings cannot be compared to results in other research since in none of the studies reviewed was there an indication whether parents referred to a first SCBU experience or otherwise.

“How sseb rigward esperienza as such peress li konna ghaddejna minnha fit-tifla, ma kienitx daqshekk hasda. Konna ppreparati minn qabel twieled il-baby....” (Mark Agius, int 3 pg 1 line 5)

“About this experience I think that as such since we had gone through it with our daughter, it was not such a shock. We were prepared from before the baby’s birth...”

“...imma fit-tifla konna hadna shock kbir, ara fit-tifel qiesna konna natu minn dak li ghaddejna allura mhux daqshekk.” (Mary Agius, int 3 pg 2 line 15)
“...but with our daughter we had a big shock, but with our son we knew what we had gone through so it was not so bad.”

In accordance with the systems theory, these parents’ reactions to their baby’s SCBU hospitalization has been shown to be due to a variety of interacting factors, rather than a simple linear cause and effect manner. It can also be noted that the cause of the parents’ reactions was similar in all cases, that of having their child admitted to SCBU. However, their different reactions, with particular differences noted between mothers and fathers, were influenced by their situation, for instance not being able to see the child after birth had particular reactions in such mothers, and so on.

All the parents in the group expressed that upon seeing that the baby’s condition was improving and he/she was making good progress, they built up courage and became less worried.

“...it-testijiet kienu tafbin, kien qed jixrob...allura jiena ma tantx inkwetajt imbaghad, qiesu mat-tielet ġurnata jiena kont dija ahjar ghax ghidt ok mela.”
(Joe Borg, int 1 pg 9 line7)
“...tests were good, he was drinking...so I did not worry so much then, by the third day I was already feeling better because I said it’s ok then.”

“...imma mbaghad taghmel kuragg tibda tarah seijjer tajjeb...” (Sue Vella int 1, pg 9 line 27)
“...but then you build up courage seeing him doing well...”
It seems that as days went by, the parents were getting more comfortable with the SCBU environment. Some parents said that their minds were at rest that the baby was at SCBU and well cared for, while another mother commented that the SCBU became like home for her which further indicates becoming progressively more comfortable and getting used to this environment. Such finding compares well to that found by Nystrom and Axelsson (2002) who found that mothers of similar term babies although they were stressed by the experience they adapted to this unexpected event.

“İktar ma ghaddew ġranet, ıktar tibda tidra u qisek thossok differenti, ıktar komdu milli fil-bidu…” (Joe Borg, int 1 pg 1 line 15)

“The more days passed, the more you get used to it and you feel different, more comfortable then before…”

“…isserrah rasek li qieghda hemm…” (Ruth Spiteri, int 4 pg 3 line 30)

“…you put your mind at rest that she is there…”

“...qieghda f’idejn tajbin li jiehdu hsiebha…” (Diane Mifsud, int 5 pg 11 line 24)

“…she is in good hands that take care of her…”

“By time qiesek tiji your home hemmhekk…” (Julie Muscat, int 6 pg 18 line 19)

“By time it becomes like your home there…”
The parents’ progressive decrease in negative emotions during the child’s hospitalization has also been found by Curran et al (1997) in their study, where similarly more positive emotions such as joy, confidence and hope were expressed by the parents in their study, more towards the end of the child’s hospitalization.

It appears that all parents realized that their child’s condition improved over a few days in SCBU and they were eager for the baby to be discharged home. One father expressed this very vividly and said that taking the baby home meant that the child was ‘normal’ in the sense of not requiring that special attention any more and so his mind would then be more at rest.

“...you just want to get out of there, ghax il-fatt li hriżt minn hemm qiesek isserrah rasek li m’ghandux bżonn iżjed dik l-attenzjoni individwali allura he is more ‘normal’.....jiena personalment dik kienet il-hin kollu fuq mohhi illi iġri johrog minn hemm, iġri narah m’ghadux bid-drip, iġri narah li neħħewlu l-pajpjijiet u iġri jiġi lejn id-dar, dak il-lsieg li jkun ghaddej minn mohhok.” (Brian Muscat int 6 pg 16 line 13)

“...you just want to get out of there, because the fact that you are out of there it is like you put your mind at rest that he does not need that individual attention any more so he is more ‘normal’.....me personally that was all the time on my mind that I could not wait that he is out of there, without the drip, without pipes and that he comes home, that is the thought that would be passing through your mind.”
In this study parents, mothers and fathers alike, could see a more positive side to their experience and disclosed that having seen other babies in SCBU with much worse conditions than their own baby, helped them to build up courage. One mother said she considered herself lucky going home with her baby when she could see other mothers having to leave their baby behind. Such a finding has not been encountered in the literature but seems to be associated with the severity of the baby’s illness where in this study infants all had minor problems and so were not as sick as other babies in SCBU.

“...tibda thares madwarek u tibda tghid ara dak u ara l-ichor, thares lejn tfal ohra taghmel kuraagg jiğiifieri s-sitwazzjoni taghna ma nahsibx kienet daqshekk estrema....” (Mark Agius int 3 pg 13 line 21)

“...you start looking around you and you start saying look at that and the other, looking at other children you build up courage I mean our situation I do not think it was so extreme...”

“...it-tifel as such ma kellu xejn hdejn ta’ haddiehor...” (Jane Borg int 1 pg 5 line 20)

“...our son as such had nothing wrong compared to others...”

“...ahna rajna lil haddiehor, tfal li ilhom hemm iktar minn taghna, rajt mothers sejrin u ser ihallu t-tfal warajhom u ghidt kemm jiena lucky li jiena ser nichdu mieghi.” (Julie Muscat int 6 pg 18 line 21)
“....we saw others, children that had been there for much longer than ours, I saw mothers leaving and having to leave their children behind and I said how lucky I am that I am taking him with me.”

One of the characteristics of the family systems theory relates to interdependence of the family members and the resultant circular causality where a change in one family member affects every other member of the family (Ashwill & Droske, 1997; Casey, 1996; Friedmann, 1997). This is very evident in the above findings where a change in the baby’s condition, as his condition improved, the parents started feeling better and less worried. Another characteristic of the family systems theory which became evident in these findings is that of family adaptation, which refers to the capacity of the family to modify their behaviour as the situation demands (Wong, 1999). Becoming comfortable with the SCBU environment and being able to find a positive side to their experience shows that parents were adapting to their situation.

It appears that in this study, parents’ reactions to their baby’s SCBU hospitalization have been similar in many ways but yet different in certain aspects, with differences even between mothers and fathers. I believe these results help midwives and nurses working with such families realize the emotional impact such an experience can have. Assessing such parents’ reactions would help them deal with this experience more effectively and adapt to their new parental roles as has been suggested by other authors (Lau & Morse, 1998; Bruns & McCollum, 2002).
Parents recalled their experiences relating to the care-giving activities they engaged in while their baby was in SCBU and it is evident that their contact with the child was initially limited to looking at the baby and stroking him.

"Ghall-bidu konna noqghodu nharsu lejh fl-inkubatur u nmelsuh xi ftit...." (Jane Borg int 1 pg 2 line 5)

"Initially we used to stay looking at him in the incubator and stroking him a little...."

"...konna ndahblu jdejna mit-twiegj ta' l-inkubatur u noqghodu mmissuh..." (Mark Agius int 3 pg 3 line16)

"....we used to put our hands into the portholes of the incubator and stroke him..."

However, later on as the child’s condition improved, more direct care was given by the parents especially by the mothers.

"...imbaghad bdejt inbiddilu n-nappy, intuh jixrob, nerfghuh u qabbadtu direct breastfeeding ukoll..." (Mary Agius int 3 pg 3 line 20)

"....then I used to change his nappy, we used to feed him, hold him and I latched him on for direct breastfeeding too..."
It seems clear that the mothers were more involved with direct care to the baby than the fathers. The care-giving activities fathers were mostly associated with were holding and occasionally feeding their babies.

Such findings are congruent with those found by Dobbins et al (1994) and Franck and Spencer (2003), who found that mothers engaged more in infant cleaning and feeding activities compared to the fathers, while both parents carried out social activities such as stroking and holding the baby. The fathers’ limited participation in care, which became evident in this study, is worthy of further discussion and ways of increasing the fathers’ involvement in their infant’s care should be sought to promote a more family-centered approach to care in the local SCBU. The interactions between family members is one of the reasons why families are considered to be systems (Morgaine,
2001). The parents' participation in their baby's care reflects their interactions with the new family member in this situation of SCBU experience.

It appears that parents, particularly the mothers welcomed the opportunity to care for their babies, they felt the need to be directly involved in hands-on activities. This can be said to relate to the openness of families, which is a characteristic of the family systems theory (Casey, 1996; Friedman, 1997; Morgaine, 2001). Welcoming the opportunity to care for the infant is a way by which such families grow, develop and adapt as input is allowed into the family system (Gillies, 1982). Recognising such parents' need to be involved in care is also central in the provision of family-centered care.

"...mbaghad meta barguh mill-inkubatur .....ghidtilha (lin-nurse) jimporta nfendi ghal rasi wahi..." (Mary Agius int 3 pg 3 line 18)

"...then when they got him out of the incubator...I told her (the nurse) do you mind if I manage on my own..."

"...bdej intouch interess, bdej nghidilhom uruni halli nbidililha n-nappy....nixtieq naghtiha l-banju lit-tifla...ghax bdej inhossni li m'insiex utli qiegheda hemm u ma nista naghmilha xejn..." (Diane Mifsud int 5 pg. 4 line 19)

"... I was getting interested, I asked them to show me so I change her nappy...I wished to give my daughter a bath... because I was feeling useless being there and I could not do anything..."
Some mothers also expressed their joy when being able to handle the baby and their sense of usefulness, which was very evident even by the look in their eyes as they spoke. One mother also said that having cared for the child in hospital gave her a sense of confidence once at home. This is similar to what is suggested by Bruns and McCollum (2002), that increasing parental involvement in infants’ care, helps develop parents’ self-confidence and efficacy.

“....once li bdejt nerfaghha, bdejt niehu izjed pijacir għax kont inhosnni utli.”
(Diane Mifsud int 5 pg 8 line 5)

“....once I started holding her, I was enjoying it because I was feeling useful.”

“....li żammejtu f’idi ghamlitli differenza lili, u li tajtu l-bottle ukoll rajtni qiesni rbah t id-dinja dak il-hin, qiesni qed naghmel xi haga ta’ barra minn hawn.” (Julie Muscat int 6 pg 5 line 13)

“...holding him in my arms made a difference to me, and giving him the bottle as well at that moment it was like I won the world, it was like I am doing something out of this world.”

“....hrigt b’kunsfidenza, ma ġejtx id-dar u panikjajt, biex nahliesha u hekk.” (Ruth Spiteri int 4 pg 7 line 25)

“....on discharge I was confident, I did not come home and panicked, to wash and so on.”

The fathers also acknowledged the need of being involved in the baby’s care. However, it seems that they felt it was more a need for the mothers rather than for
themselves. Once the situation allowed the parents to handle and care for the baby more, the fathers preferred to let the mothers do more of the baby’s care. Such an attitude may be a result of society which traditionally may have dictated that fathers have no role in the care of their newborn and that this is predominately the mother’s role (Vine, 1995).

“...qiesni peress li hi (il-mara) kienet nieqsa mit-tifla iktar kont inhalli lilha (il-mara) maghba…” (James Mifsud int 5 pg 5 line 6)

“.... Since she (my wife) was away from our daughter I used to let her (my wife) with her…”

“...li tiehu hsiebu inti f'mohhok tghid li t-tarbijja ġejja iktar ghan-normal, m'ghandhix bżoum dik iċ-ċerta attenzjoni professionali, barra minn hekk ovjament inti trid, you need to touch and handle your baby, hands-on tridha iżjed u iżjed nahseb jiena l-mother.” (Brian Muscat int 6 pg 17 line 28)

“...taking care of him yourself in your mind you say that the baby is progressing towards normality, does not need that professional attention any more, apart from that you obviously want to, you need to touch and handle your baby hands-on, you want that more and more so I think for the mother.”

Only one mother did not perceive the need as such to engage in care-giving activities such as nappy changing and bathing. In this case the mother’s priority in care-giving was breastfeeding, other aspects of care seemed less important particularly this being her third child. This can be seen to reflect family boundaries, which is an imaginary but real line that exists between the family and its environment (Stevenson-Hinde,
This characteristic of the family systems theory is reflected here as the mother is being selective of the input into her system, welcoming the opportunity to participate into her chosen aspect of care rather than others. According to Casey (1996), understanding such boundaries is essential to make a thorough assessment of family health care needs. This finding helps to emphasise that different family members may differ in the aspects of baby care which they would like to engage in and Laurie (1995) argues that in providing family-centered care, this should be acknowledged and respected.

“... ghalija l-fatt li irnexxili breastfeeding, ghalija kienet biżżejjed... speci għidt nilhaq nahšlu u nbiddilu” (Sue Vella int 2 page 13 line 25)

“...for me the fact that I succeeded in breastfeeding, for me it was enough...I said there is ample time to wash and change him.”

4.2.3 Barriers to child care

All parents perceived that the baby’s condition in the first few days of hospitalization as being a barrier for them to have direct contact and care for their baby. This was particularly associated with procedures and equipment attached with the babies. Such results seem to indicate that in the local setting, parents’ participation in care is predominantely lacking in the initial stages of an infant’s hospitalization in SCBU.

“...ma stajniex ghax kien hemm haflna afferijiet li ma stajniex nihhendijawhom... kellu anke l-line miż-żokra.” (Joe Borg int 1 pg 2 line 26)
“...we couldn't because there were a lot of things which we could not handle...he even had an umbilical line.”

“...sakemm kien fl-inkubatur, jien ma stajtx niszqeh...kellu hafna pajpijjet u anke kellu pajp miż-żokra, dak jekk jinqalalu qaluli dak vera jwegża biex tagħmihlu. (Mary Agius int 3 pg 3 line 10)
“...until he was in the incubator, I could not feed him...he had a lot of lines, he even had an umbilical line, and they said if that is dislodged it is painful to do.

Another aspect which can be regarded as inhibiting parents’ participation in the baby’s care relates to them being afraid or uncomfortable doing certain aspects of care. This has been disclosed by three participants in the study. Similarly, Coyne (1995) suggests that parental anxiety may limit the extent of involvement that some parents feel able to engage themselves into initially. Hence, reassuring such parents and being sensitive to their feelings may help increase their participation and involvement in care. Yet, Redman (1993) and Glen (1989) argue that parents should not be pushed into participation until they are ready to do so.

“...xtaqt kieku niehdu hsiebu imma kont nibża minhabba l-line taż-żokra li naqlaghulu u mbaghad ikollhom jergghu jagħmlulu, ma rridx hekk imbaghad.” (Jane Borg int 1 pg 10 line 2)
“...I wished to take care of him but I was afraid because of the umbilical line that if I dislodge it for him then they would have to do it again, I did not want that then.”
"...anqas li kieku qaluli ma kont nisqieh u nbiddillu, I would not dare, ma kieux inhossni komdu fis-sens ghax kont narah fragli." (Brian Muscat int 6 pg 19 line)

"...not even if they told me I would not have fed or changed him, I would not dare, I did not feel comfortable in the sense that I saw him as being fragile.

"...jien niddejjaq min joqghod ihares lejja jien u nahslu jew hekk....hemmhekk (SCBU) m'hemmx dik il-privacy trid taghmel kollox quddiem kulhadd" (Sue Vella int 2 pg 13 line 28)

"...I do not like it when others look at me while I wash him and so on...there (in SCBU) there isn’t that privacy you have to do everything in front of everyone."

Some mothers also perceived being physically unfit to do certain care-giving activities for their baby. This was particularly associated with mothers, in the early days after having had a caesarean section.

"biex inkun onesta ma tantx flaht, anqas kelli sahha naghmel xejn....bdejt inhossni diżutli anke biex inqum bil-wieqfa sew, jiġifieri thank God li kien hemm min jiehu hsiebu." (Sue Vella int 2 pg 6 line 3)

"to be honest I did not feel well, I did not have the energy to do anything.... I felt useless even to stand up properly, I mean thank God that there was someone to take care of him."

Such inhibiting factors identified by the parents in caring for their baby have not been encountered in studies reviewed possibly due to the more quantitative designs of such studies, while the more in-depth data obtained in this study allowed for such barriers
to parents’ participation to come to light. Having identified such inhibiting factors has implications for practice particularly in the local setting, where reducing such barriers may help adopt a more family-centered approach to care. Barriers to parents’ participation in care may be viewed as inhibiting the parents’ interaction with the new family member and so causing disruption in family functioning. Decreasing the identified inhibiting factors, particularly by encouraging more parental contact with the child in the initial stages, can help stabilize the family system and move the family in a direction that promotes family functioning.

4.2.4 Bonding with baby

Upon narrating their experiences, parents explored the issue of parent-infant bonding and how this was affected by their SCBU experience. All parents in this study expressed that having their child in SCBU hindered their initial bonding with the baby. Separation from the baby and lack of initial direct contact with their baby can be considered as the parents’ main reasons why they felt that having their baby in SCBU had a negative influence on their bonding with the child. This issue of having parent-infant bonding disrupted as a result of separation due to the child’s hospitalization in SCBU has been highlighted by other authors namely, Gale and Franck (1998) and Pearson and Anderson (2000), who from their studies suggest that parent-infant separation and the lack of parents’ involvement in care may increase the risk of parenting disorders.

“...ma kienx herm daqshekk kuntatt ghalhekk nahseb li fixkel il-bonding...kien fl-inkubatur.....ma tantx stajna nihhendijawh.” (Jane Borg int 1 pg 22 line 29)
"...there was not so much contact that is why I think that it hinders the bonding...he was in the incubator...we could not handle him so much..."

"...rigward bonding, il-fatt li ma tkunx tista tihhendilja l-baby minhabba li qieghed fl-inkubatur b'dawk ic-ċertu kundizzjonijiet, thossha naqra nieqsa..."  
(Brian Muscat int 6 pg 17 line 14)

"...about bonding, the fact that you cannot handle the baby because he is in the incubator with certain conditions, you feel it a bit lacking..."

The fear that something might happen to the baby was also considered by two mothers as hindering their bonding with the infant. This is similar to what has been put forward by Kenner (1992), who suggests that parents of SCBU infants may be reluctant to establish a relationship with their sick baby in case the child dies. During the interviews it could be noted that this issue of bonding being hindered in SCBU was a major issue for these two mothers particularly since they referred to this several times and even their non-verbals especially their facial expressions as they recalled this aspect, showed that this was a salient part of their SCBU experience.

"...anqas ridt inhares lejh hafna x'hin qaluli li ser itellghuh ghax ghidt jekk jiġri xi haja, qiesni ma ridx nibbondja mieghu il-baby, ħarist lejh hekk mill-ġenb..."  
(Sue Vella int 2 pg 3 line 12)

"....I did not want to look at him a lot when they told me that they were going to take him up because I said if anything happens, I did not want to bond with the baby, I just look at him from the side..."
"...I-SCBU taqta’ dik il-bond ghax ikkolok ċertu biża, dik nahseb jien ghax tidhol il-biża fin-nofs li allahares qatt jiğrilu xi hağa.” (Julie Muscat int 6 pg 17 line 11)

"...SCBU hinders bonding because you have a certain fear, that is what I think, that you become afraid that godforbid something happens to him.”

One of the fathers also said that his limited visiting when the baby was in SCBU, due to work commitments, hindered his bonding with the child.

"...bhala bonding iktar setghet taghmel l-omm milli jiena, ghax kont immur saghtejn biss.” (Mark Agius int 3 pg 15 line 9)

"...it was more the mother than me that could bond, because I only used to go for two hours.”

Most of the mothers and some of the fathers acknowledged that parent-infant bonding increased once the baby’s condition improved and they had more direct contact, when the baby was more accessible to them. Possibly this occurs because as the child’s condition improves, the fear of the child dying reduces and the increased contact with the child allows for the initiation in parent-infant bonding. This appears to suggest the need for parents to participate and be involved in care as early as possible in the child’s hospitalization in order to allow parents to establish a parent-infant relationship as early as possible.

"...il-bonding ġie iktar meta nehhewlu l-affarrijiet ghax qabel ma stajtx nerfghu, kont inmisslu fit idejħ meta kienu jifthulna t-twiegħ ta’ l-inkubatur.” (Mary Agius int 3 pg 29 line 29)
“...there was more bonding when they removed the things he had because before I could not hold him, we used to stroke his hand when they opened the incubator portholes for us.”

“...once li bdiet taghthieli f’idi, iva bdejt nibbondja ....imma tkun fl-inkubatur ma tantx tista.” (Diane Mifsud int 5 pg 13 line 11)

“...once she was given to me to hold, yes I started bonding...but when in the incubator you cannot.”

Two mothers and a father extended the issue that there was more bonding when the child was more accessible to them, by saying that parent-infant bonding occurred more once they were at home with the baby. This seems to suggest that once at home, the baby’s care is shifted from the hospital setting to the home environment where parents have the ultimate care of the baby with no further care by professionals and so this allows for more bonding with the baby to occur.

“...l-bonding nahseb iktar ghamiltu kemn ilu hawnhekk id-dar milli qabel hemmhekk l-SCBU” (Mark Agius int 3 pg 15 line 16)

“...I think I bonded more since he has been here at home than before in SCBU.”

“...il-bond iktar ġiet meta ġejt id-dar....bdejt inżommu iżjed miegli, bdejt breastfeeding iżjed.” (Julie Muscat int 6 pg 17 line 8)

“...I bonded more when I came home...I started holding him more, giving him more breastfeeding...”
The family systems theory emphasizes the interaction between the members of the family. However, results show that the parents had difficulty in achieving a sense of closeness with their infant in SCBU which indicates that interactions between members were not appropriately achieved suggesting that ways for enhancing such interactions in this setting should be sought and so adopting care which is more family-centered.

4.2.5 **Staff behaviours and attitudes**

Analysis of the parents' accounts revealed that staff behaviours and attitudes had considerable influences on their experiences in SCBU. This theme brings out interactions between different systems, the mother-father-infant, comprising the family system and the staff in SCBU, representing the health care system in this setting. Staff played a major role in providing parents with their various needs in SCBU, especially information needs about their baby and their need for participation in care which are the sub-themes that emerged from this theme.

4.2.5.1 **Need for information**

Giving information to parents is considered as a way by which parents become knowledgeable and active partners in caring for their baby together with the staff. Most parents said that midwives and nurses working in the unit provided them with information about the baby. Such information concerned mainly, daily updates about
infant progress and changes in medical status which is similar to what was found by Bruns and McCollum (2002) in their study.

"...jghidulek x'inhu jiğri....kuljum konna nkunu naľu." (Jane Borg int 1 pg 17 line 11)

"....they tell you what is happening....everyday we used to know."

"Kollox kienu jinsurmawna, minn x'hin konna nidhlu (I-SCBU)...." (Mary Agius int 3 pg 6 line 21)

"They used to inform us about everything, as soon as we entered (SCBU)...."

The findings also indicate the parents' need for clear, unhurried and multiple explanations, which conform with what is suggested in the literature (Lau & Morse, 1997; Taylor, 1996), to aid parents understanding. Providing information to parents can be regarded as input into the family system (Friedman, 1997; Gillies, 1982), from the health care system and so as discussed above relates to the interaction between two systems. Information giving highlights the importance of communication between these two systems which allows the family's adaptation according to the situation.

"....fit minn nurses sa ġabu siğgu qaghdu bil-qiegheda hdejna jkel'muna u jfchmuna kollox." (Julie Muscat int 6 pg 10 line 2)

"....some of the nurses even got a chair and sat beside us to talk and explain everything to us."
"...they would sit down and explain over and over again, how many times necessary." (Brian Muscat int 6 pg 3 line 28)

In the local SCBU, a midwife or a nurse is allocated to a baby or two on day to day basis, depending on the intensiveness of care required and on the number of babies present on the unit and the number of staff available. In this study, parents shared different opinions regarding their awareness of the nurse/midwife caring for their baby on particular days while in SCBU. It seems that for the parents it was very important to know who is caring for their baby and most used to ask who is allocated to their child as soon as they visited the baby. One couple said that the allocated nurse or midwife used to approach them when she saw that they were visiting their baby. These findings appear to indicate what Fenwick et al (2001) found in their study, that knowing who is caring for the baby was considered a way of gaining access to the infant.

"kont nghid min hu fuqha llum, u min ikun konna nsaqsu liha fuq il-baby..." 
(Diane Mifsud int 5 pg 6 line 29)

"I used to ask who is caring for her today, and whoever it was we used to ask her about the baby..."

"...x'hin konna nitilghu, l-ewwel haga kienet tiqi n-nurse u kienet tghidli illum jien qieghda mal-baby u tibda tghidli fuq..." (Mary Agius int 3 pg 23 line 13)

"...when we used to go, the first thing the nurse used to come and tell me today I am taking care of the baby and she used to start telling me about him..."
Parents expressed that they used to seek explanations about their baby by asking questions to midwives and nurses, particularly those caring for their baby. They said that they felt comfortable asking the staff and that their questions were always answered which indicates that the staff were supportive of the parents’ information needs and suggests that relationships between parents and staff had developed. Bruns and McCollum (2002) found that parent-staff relationships are more likely to occur with increasing parental amount of contact in the unit and as would be shown in the last theme of ‘visiting the baby’, most parents in this study spent a lot of time in SCBU which may indicate why parents felt comfortable asking questions of the staff.

“...ahna konna nsaqsu hafna u ma kien hemm l-ebda question li konna niddejqu nsaqsu, kienu jieqfu u jghidolek...inti ssaqsi lil minn qed jiehu hsiebu....tkun taf x’inhu ghaddej, kull x’hin issaqsi dejjem iwiegbuk u tara li mhux qed iddejaqhom speci, thossok komdu li ssaqsi.” (Joe Borg int 1 pg 5 line 14)

“...we used to ask a lot and there was no question that we used to feel uncomfortable asking, they used to stop and tell you....you ask whoever is taking care of him...you would know what is going on, whenever you ask they always answer you and you can see that you are not annoying them, you feel comfortable asking.”

“...ahna konna nsaqsu hafna... u meta saqsejniehom xi haga spjegawlna kollox...kienu jzommuna nfirmati hafna.” (Mary Agius int 3 pg 21 line 17)

“...we used to ask a lot....and when we asked them something they explained everything....they used to keep us very informed.”
Phoning the staff at SCBU during the night, was another way how parents obtained on-going information about their baby and which provided parents with reassurance. Such a way of obtaining information about the infant has not been encountered in the literature yet this study shows that such a means of communication between the staff and parents was useful.

"...kont incempel bil-lejl...bil-lejl kont inqum nara x'hin imissu feed, nhalli nofs siegha, imbaghad ncempel u nsaqsihom kif inhu u kienu jghiduli li alright, li xorob u daqshekk u tkun mohhok aktar mistrieh ghax ma kontx nistenna minn x'hin tlaqt sa l-ghada." (Joe Borg int 1 pg 4 line 19)

"...I used to phone during the night...at night I used to get up and check at what time he was due for a feed, I leave half an hour, then phone and ask them how he is and they used to tell me that he was alright, that he drank and that's it and your mind is at rest because I did not have to wait from when I left till the next day."

"...jien kont incempel bil-lejl ukoll...kont incempilhom u nsaqsiehom kif inhu...u dejjem sibthom ta' ghajnuna." (Mary Agius int 3 pg 4 line 20)

"...I used to phone at night as well...I used to phone them and ask them how he was...and I always found them helpful."

Throughout their experience in SCBU it is evident that parents noticed various differences between staff attitudes and behaviours particularly when it came to providing them with information about their child. Parents noted that some staff were more approachable and helpful than others, in three cases sufficient information was not provided, while in two others the parents felt they were being given personal
attention from the staff. Such findings are similar to those put forward by Curran et al (1997), Wereszczak et al (1997) and Miles et al (1999) who also found that staff behaviours and attitudes differ in providing parents in SCBU with their information needs.

“…tkun wahda minn ohra thossok iktar komda isqaṣi…jien nahlseb anke l-karattru, wahda minn ohra ikollha xi ḥāqa li tiqbdel, turi iktar li trid titkellem.”

(Jane Borg int 1 pg 5 line 5)

“…from one staff to another you feel more comfortable to ask…I think even the character, one staff would have something that attracts you more than another, showing that she wants to discuss.”

“…kien hemm min nofs kliem, kien hemm wahda partikolari… responseData, fil-qasir u titlaq…” (James Mifsud int 5 pg 5 line 15)

“…there were staff who did not say much, there was one particularly…you ask her a question, she answers briefly and leaves…”

“…certu staff ma jaghtux spjegazzjoni ta’ kollox…” (Diane Mifsud int 5 pg 5 line 19)

“…some staff do not give you an explanation for everything…”

“Fl-SCBU I felt li avolja dan hdejn babies ohra ma kellu xejn pero xorta hassejt dik l-attenzjoni u l-importanza li jiena I am an individual mhux just hekk a number, hassejt li I was someone important.” (Sue Vella int 2 pg 6 line 20)
“At SCBU I felt that although my baby had nothing compared to other babies, still I felt that attention and importance that I am an individual not just a number, I felt that I was someone important.”

Parents also expressed that apart from the midwives and nurses, paediatricians also provided them with information about their baby. This seemed to be an important aspect of care for the parents.

“... meta konna nitilghu fuq xi l-hdax, tooqghod hemm u imbaghad tigi t-tabiba jew tabib u jdur kull baby u kif tasal hdejk tghidlek ghamiulnu hekk, qed nistennew hekk, issaqsieha...” (Joe Borg int 1 pg 17 line 21)

“...when we used to go up around eleven, we used to stay there and then the doctor comes and goes near each baby and when she comes next to you she tells you we did this for him, we are waiting for this, you ask her...”

“...anke t-tobba konna niehdu pjačir jiġu jkellmuna u jghidulna x’qed jiġri.” (Mary Agius int 3 pg 25 line 21)

“...even the doctors we used to appreciate that they come and speak to us, tell us what is happening.”

However, not all parents obtained sufficient information from the paediatricians, one couple recalled how they were not told what was wrong with their baby until almost discharge and that they had very little contact with the doctor.
“...haqa li dejqietni li ma kontx na'f x'ellha t-tifla, ma qalulix u sirt na'f lejn l-ahbar, haduha for granted li jiena kont na'f imma ma kontx, ma kien qalli hadd.”
(Ruth Spiteri int 4 pg 2 line 26)

“...something which annoyed me was that I did not know what my daughter had and I got to know at the end, they took it for granted that I knew but I did not, no one had told me.”

“it-tabib ma kienx ikun hemmhekk kien izurhom kollha u daqshekk.” (Anton Spiteri int 4 pg 8 line 28)

“the doctor was not there, he used to visit them all and that’s it.”

Parents considered the midwives and nurses to be very supportive to them during their experience in SCBU and described several ways in which they believed the staff offered them support. Parents expressed that the support they received from staff took the form of: information giving, reassurance, encouragement, co-operation and patience. Such findings compare well with those found by Miles et al (1999) and Wereszczak et al (1997) where parents in their studies similarly identified such staff characteristics as being supportive to them.

“l-istaf’kienu haflna ta’ support ghax huma kienu jghidulna x’inhu jigi” (Mary Agius int 3 pg 21 line 16)

“the staff were very supportive because they used to tell us what was going on.”

“jghinu haflna l-istaf, jaghutuk kuragi...il-hin kolhu ji’gu, toqghodx tinkwieta.”
(Joe Borg int 1 pg 4 line 4)
"the staff help a lot, they encourage you...they are all the time coming and telling you not to worry."

"Minn naża ta’ l-istaff sibt koperazzjoni u paċenzja." (Brian Muscat int 6 pg 7 line 5)

"From the staff I found cooperation and patience."

This study’s findings therefore suggest that the parents’ perceived needs in SCBU predominately related to information and support needs and these have also been found to be important participation needs in other studies (Bass, 1991; Hurst, 2001; Ward, 2001; Bialoskiorski et al, 2002). However, although this study has shown that staff are generally perceived favourably in meeting such parental needs, one needs to guide efforts at improving staff behaviours and attitudes towards parents’ participation and so family-centered care, which as has been shown may not always be supportive to parental needs.

4.2.5.2 **Need to care for baby**

Parents’ experiences have shown that staff behaviours and attitudes also had an influence on their participation in their baby’s care while in SCBU. These findings show how the interactions of the family with the staff representing the health care system, influenced family functioning in SCBU.

Two breastfeeding mothers expressed both positive and negative attitudes by the staff in SCBU regarding breastfeeding.
"...għall-breastfeeding ma kellix l-istess tip ta’ għajnuna, kien hemm min inkorragini iktar minn haddiehor...jiena kont ninsisti hafna li ridt naghtih il-breast, kien hemm min jghidli qiesu ma jridx ħallieħ, issa erga pprova later, ma qallulix ma naghtihx ta, imma biex npprova aktar tard, imma kien hemm min baqghu mieghi sakemm xorob....fil-fatt kont nghid ħalli nara lil min ser ninzerta...ridt lil xi hadd li vera jghini.” (Sue Vella int 2 pg 16 line 1)

"...for breastfeeding I did not have the same type of help, there were those who encouraged me more than others...I used to insist that I wanted to breastfeed, there were those who used to say that he does not seem to want, leave him and try later, they did not tell me not to give him, but to try later, but there were others who stayed with me until he drank...in fact I used to say let me see who it will be....I wanted someone who really would help me.”

"...l-iktar haġa li dejqietni hemmhekk, meta jien ppruvajt naghtiha breastfeeding u nekspressja u kien hemm wahda....qabdet tatha l-bottle u jien ma rridx naghtiha bottle...dik dejqietni dik il-haġa, ghax kont ghidtilhom ċar biex icempluli (għal breastfeeding), dik il-bqija kien hemm oħra qagħdet mieghi nisqi l-baby minn naħa u nekspressja mill-oħra, qagħdet iżżomli l-pompa bi, jiġifieri differenza totali.” (Ruth Spiteri int 4 pg 2 line 18)

"...the thing that annoyed me the most there, when I tried to give her breastfeeding and expressing and there was one .......she just gave her a bottle and I did not want to give her a bottle...this thing really annoyed me, because I had told them clearly to phone me (for breastfeeding), only that otherwise there was another one who stayed with me breastfeeding the baby from one side and
expressing from the other, she was holding the breast pump for me, I mean a total difference.”

Staff behaviours and attitudes also had an affect on the parents’ participation in other aspects of the baby’s care. All mothers but only one father recalled how they had been encouraged and shown how to carry out certain aspects of baby care. Such a facilitative and educative role of the nurse/midwife working with families is emphasized by Ahmann and Johnson (2000), while Heerman and Wilson (2000) similarly extended this view by stressing that sharing of knowledge and skills are necessary for improved parental participation.

“...urewni kif nahlilha...l-ewwel kont hemmhekk u assistejt biex nara din it-tifla x’ghandi naghmel u ma naghmlx ....tawni ċ-ċans li jiena nitghallem....tawni ċ-ċans li nbidielha u nisqieha biex nitghallem ghax jiena ridt nitghallem kif niehu hsiebha ghal meta tiği d-dar” (Diane Mifsud int 5 pg 4 line 26)

“...they showed me how to wash her...first I was there and I assisted to see what I have to do and not with this girl....they gave me the chance to learn...they allowed me to change her and feed her so I learn because I wanted to learn how to take care of her for when I come home.”

“...qaluli eja papa halli tbiddillu...do it yourself speci...jigiżieri I was encouraged, mhux halli f’idejina...” (Paul Vella int 2 pg 14 line 12)

“...they told me come on daddy so you change him....do it yourself like...so I was encouraged, not leave it to us...”
The fact that only one father in this study recalled being encouraged to care for the baby, indicates that fathers are not encouraged enough to participate in their baby’s care and this seems to reflect what has been discussed earlier, that the father’s role in infant care is still predominately missing. Surely this suggests that this aspect of FCC is deficient in the local SCBU and efforts need to be directed at increasing the fathers’ involvement in caring for their baby.

Two mothers also expressed how staff attitudes and behaviours differed, with some involving them more than others in their baby’s care while in SCBU. This may reflect what has been repeatedly documented in the literature, that nurses and midwives providing neonatal intensive care seem to have different perspectives towards parent participation (Cardoso, 1991; Dobbins et al, 1994). Different authors have indicated that some nurses still view parent participation as challenging their nursing role, threatening their identity and authority or seen as an intrusion into their territory (McGrath, 2001; Coyne, 1995; Fenwick et al, 2001). Heerman and Wilson (2000) found in their study that nurses felt intimidated and a loss of control with parent participation.

“...kien hemm min iktar jinvolvik, biex terfghu, tbiddillu n-nappy u bekk u min inqas jinkoraggik tiehu hsiebu.” (Jane Borg int 1 pg 9 line 22)

“...there were those who involve you more, to hold him, to change his nappy and so on and those who encourage you less to take care of him.”

“...kien hemm min jinvolvik iktar minn haddiehor...kollha jghinuk imma kien hemm min iżjed...” (Ruth Spiteri int 4 pg 4 line 6)
"... There were some who involve you more than others... they all help you but there were those who would more..."

Such findings are coherent to what Fenwick et al (2001) found in their study, namely that mothers can identify nursing actions which either encourage or restrict their participation in their infant's care. Similarly, other authors have indicated that staff attitudes and behaviours can either facilitate or hinder the nature and extent of parents' participation and so a move towards family-centered care (Heerman & Wilson, 2000; Franck & Spencer, 2003; Espezel and Canam, 2003).

4.2.6 Visiting the baby

4.2.6.1 Parents' visiting

Parents discussed the time they spent visiting their baby in SCBU and it can be noted that in the initial days of the child's hospitalization, the parents' visits depended on the mode of delivery. Following a caesarean section mothers did not visit in the first day and then started visiting with increasing duration as they were physically feeling better in the following few days. In such cases it was more the father who visited the baby initially then both parents started visiting together spending most of the available visiting time next to the child. One couple also added that they visited the baby more when they could handle the child, after a few days.
"...l-ewwel ġurnata jiena ma tlajtx, hu tela hdejh...it-tieni ġurnata speci tlajt fit...pero l-ghada bdejt inbossmi alright, bdejt nitla iktar ta’ spiss...” (Julie Muscat int 6 pg 11 line 24)

"....the first day I did not go, he went near him...the second day I went up a little...but the next day I was feeling alright, I started going up more often...”

"Nahseb meta nehnewlu l-wires u l-affarijiet li kellu mieghu, meta stajna noħorguh mill-inkubatur iżjed konna immorru...wara tliet ijjem konna ndumu iktar mill-ewwel tliet ijjem...anke hi (il-mara) fizikament kienet abjar...iktar ma kien aċċessibli ghalina iktar qattajna hin hemmhek.” (Mark Agius int 2 pg 8 line 10)

“I think when they removed the wires and the things attached to him, when we could take him out of the incubator we used to visit more...after three days we used to stay more than the first three days...even physically she (my wife) was better...the more he was accessible to us the more we spent time there.”

"...konna nqattu l-hin kollu hemm, jiena kont bil-leave, konna nitilghu fil-hdax u konna nocqoqdu sas-sitta hemmhek.” (Joe Borg int 1 pg 2 line 1)

“...we used to spend all the time there, I was on leave, we used to go up at eleven and stay till six there.”

The only two studies encountered in the literature and reviewed, which explored parents’ visitation in SCBU were those by Franck and Spencer (2003) and Dobbins et al (1994). However, findings from these studies cannot be compared to those found in this study since these studies (Franck & Spencer, 2003; Dobbins et al, 1994) made no
reference to parents’ visiting in the early days of hospitalization and the baby’s mode of delivery, which have been found to be two very important factors related to parents’ visiting in SCBU in the present study.

Where the father returned to work soon after the birth of the child, this resulted in reduced visiting by the father, while the mother spent more time in SCBU. The fact that the father’s demands of work resulting in less visiting, is coherent with what other studies have found (Giacodia et al, 1995; Brown et al, 1989; Callahan et al, 1991 and Lewis et al, 1991) and the resultant increase in mothers’ visiting is similar to what Franck and Spencer (2003) found in their study.

"Iktar jien kont immur ghax hu peress li minhabba x-xoghol ma setghax jaghmel mod iehor, iktar jien kont nitla u kont inqat ta sieghat hemmhekk....mbaghad x’hin jiği r-rağel konna nitilghu flimkien." (Mary Agius int 3 pg 5 line 17)

"I used to go more because due to his work and not being able to do otherwise, I used to go up more and used to spend hours there...then when my husband comes we used to go up together."

"...jiena kont xoghol ...kont immur xi tlett sieghat kuljum." (Mark Agius int 3 page 2 line 27)

"...I had work...I used to go about three hours every day."

Parents’ visiting in SCBU indicates the parents’ need to interact with the infant which as has been highlighted earlier, the interactions between family members are
fundamental to the family system. The need for such parents’ interaction indicates their inclusion of the new family member into their already existing system.

In their accounts, parents also discussed the local SCBU visitation policy (appendix G) and all parents spoke about their views on the timing available for visitation by parents, which is daily from 11am till 6pm. Some said they wished to stay next to the child longer, others said there was enough time for them to visit while some others, especially fathers, said that their other responsibilities such as family and work made it difficult for them to visit for long periods within these available times.

“...jiena kont inhossa diffiči li irrid ninżel...ghax imbagħad sa filghodu hemm ħafna ħin.” (Jane Borg int 1 pg 6 line 30)

“...I used to find it very difficult that I have to go down...because then till the morning there is a long time.”

“...li stajt nagħmel 24 hours hemmhekk kont nagħmilhom.” (Ruth Spiteri int 4 pg 4 line 19)

“...if I could spend 24 hours there I would have.”

“...hin biżżejjed hemm, imma fil-każ tieghi kelli problema ghax irrid niehu hsieb it-tifla jiġisseri irrid nagħzel jew inhalli t-tifla ma’ ommha jew inkella ħa niehu hsieb it-tifla jien.” (Mark Agius int 3 pg 9 line 26)

“...there is enough time, but in my case I had a problem because I had to take care of my daughter so I had to choose either I leave her with my mother in law or take care of her myself.”

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These findings clearly indicate that different families have different views and different needs regarding visiting in SCBU. Cuttini et al (1999) who compared visitation policies across eight European countries, suggest that visitation policies should be flexible, accessible and responsive to the families’ needs and the above findings indicate that a more liberal visiting policy for parents should be considered locally. The ability of the parents to visit as frequently as they wish is considered important if both parents are to be involved in the care of their infants (Laurie, 1995).

Such a need for change in the current policy has been noted by most parents, especially fathers who offered various suggestions in order to improve the current timings for parents’ visiting in SCBU. Probably it was more the fathers who made such suggestions because they were the ones affected by the visiting times available since the mothers were still hospitalized in the postnatal ward and so could utilize more the available visiting time.

“...iżżidu l-hinijiet, il-visiting hours ghall-parents.” (Joe Borg int 1 pg 11 line 7)
“...add more time, the visiting hours for parents.”

“...per ħempju min jahdem sal-hamsa kull ma jkollok siegħa kuljum biex tmur li ma nabsibx illi huwa bijżejjed u mhux fajr ghal missier lanqas, għax l-omm tkun hemmhekk, jiġifieri ghandha ċ-ċans meta trid....allura forsi jkun hemm ilttar flexibility mhux ser nghiddlek sa nofs il-lejl imma forsi sat-tmienja jew sa l-ghaxtra.” (Mark Agius int 3 pg 10 line 12)
“...for example those who work till five all you have is an hour every day to go which I do not think is enough and it is not fair for the father either, because the mother is there, so she can go when she wants...so there maybe could be more flexibility I am not saying till midnight but maybe till eight or ten.”

“...mill-hdax sas-sitta huwa bin tajeb hafna pero kont nippreferi li kien ikun hemm break in between ta’ forsi siegha u nofs, saghtejn u jitwal il-hin minflok sas-sitta jiği sat-tmienja...trid izomm f’mohbok li jekk inti ghandek xi hadd iejor fil-każ li jkollok tfal obra trid tiehu hsiebhom, vera li ssib l-ghajnuna mill-familja imma xorta wahda trid tarahom...u mis-sitta sal-hdax ta’ filghodu ghandek hin twil sakemm inti tista terga tmur tarah.” (Brian Muscat int 6 pg 10 line 30)

“....from eleven till six is very good timing but I would have preferred if there was a break in between of maybe an hour and a half or two, and there is then more time instead of till six it becomes till eight....you have to keep in mind that if you have someone else, in the case of having other children that you have to take care of, it is true you find help from the family but still you have to see them...and from six till eleven you have a long time until you can go again to see him.”

Mothers and fathers in this study agree that only parents should visit at the SCBU next to the baby, particularly due to the increased risk of infections if more people visit next to the babies, because of confusion which may be created when there are more people and also because other parents may not like it. The unit set-up was also considered as not being appropriate for more people other than the parents to enter
next to the baby since it comprises mainly of a large ward having a number of babies next to each other. During the interviews this issue of parents only entering next to the baby was noted to be strongly agreed upon by all parents and the emphasis with which they spoke indicates that they seemed to have had no doubt about it. This may suggest that although change in the present local policy may be indicated, however, this issue of visiting should remain as is, since it is in accordance with the parents’ wishes. Although, a study with a larger sample of parents could help determine whether this is what the majority of parents believe.

“Jiena dik toghgobni li l-ġenituri biss jidhlu minhabba infections u hekk…”

(Anton Spiteri int 4 pg 4 line 22)

“I like it that only parents go in because of infections and so on…”

“…naqbel li jidhlu l-ġenituri biss…..tevita li jkun hemm ċerta konfużjoni …..u haddiehor jaf ma jiehux pjaċir…” (Brian Muscat int 6 pg 13 line 13)

“…I agree that only parents go in...you avoid a certain confusion...and others may not like it…”

“…din hija kamra kbira u mhux kulhadd ghandu l-baby f’kamra ghalih....ejja nghidu jiena jiġu ommi u missieri, ommha u missierha, jiġu jidhlu, hemm parents ohra...hemm min ikun qed ihossu down u jiġi xi hadd jiċċaċra... are kemm hu helu, forsi haddiehor ihoss hux.” (Joe Borg int 1 pg 8 line 16)

“…this is a large room and not everyone has the baby in a room on its own...let’s say my mum and dad come, her mum and dad, they come in, there are other
parents ....others may be feeling down and then someone comes prating...look how sweet he is, maybe others feel hurt.”

Breastfeeding mothers recalled that they had been allowed to breastfeed their baby any time of day and night and not within visiting hours only. This is in accordance with the Breastfeeding Policy which is incorporated within the SCBU Visiting Policy (appendix G). This may be considered as a very positive aspect of family-centered care and something which should continue to be encouraged.

“....kienu jčempluli anke bil-lejl biex nitla ntieh breastfeeding.” (Jane Borg int 1 pg 10 line 20)
“....they used to phone me even at night to go and breastfeed him.”

“....anke wara ċertu hours xorta lill-mother ihalluha titla....biex naghti breastfeeding.” (Julie Muscat int 6 pg 9 line 20)
“...even after certain hours the mother is still allowed to go up....to breastfeed.”

One father also said how the staff had allowed him to pay quick visits to his baby even outside visiting hours. This shows that although the local visiting policy has restricting visiting times, yet it seems that enforcement is up to staff discretion. According to Griffin (2003) such situations can be a cause of conflict and this seems to emphasise why visiting times need to be more liberal and according to parents’ needs.
“...jiena ġieli tlajt f’hinijiet mhux eżatt tad-dhul...minn naха taghhom dejjem sibt koperazzjoni jekk kont nitlobhom biex nittawwallu two minutes, yes pero ovjament ma kontx indum.” (Brian Muscat int 6 pg 7 line 13)

“...sometimes I went at times which are not exactly the visiting times....from their side I always found cooperation if I asked them to see him for two minutes, yes but obviously I would not stay long.”

4.2.6.2 Visiting by siblings

Parents who had other children discussed the issue of visiting by siblings in SCBU. According to the Visiting Policy (appendix G) siblings are allowed to visit, accompanied by both or either of parents on admission and every Sunday between 3.45pm and 4.45pm from behind the viewing glass. Research involving visiting in SCBU by siblings is unfortunately lacking but Laurie (1995) identifies that siblings should be encouraged to visit since they are part of the family unit.

Three couples had other children in this study where three mothers and one father expressed that they wished their other children to see the baby when in SCBU, however one mother did not agree that her children see the baby on admission. The other two fathers did not agree that children should enter the SCBU.

“...xtaqthom hafna li jidhlu jarawh, it-tifla ghada tghidi mhux far mama ma rajnielx lill-baby taghna ahna (meta kien l-SCBU). Kienu ġew imma ma hallelwhomx jidhlu ghax ma kienx il-bin li suppost. Ma kontx irridhom jarawh kif
"...I wished a lot that they go in and see him, my daughter still tells me it is not fair mummy we did not see our baby (when he was in SCBU). They had come but they did not let them in because it was not the appropriate time. I would not have wanted them to see him when he was in the incubator, I would not have wished them to see him like that no, but once he was in the cot alright."

"...no I do not agree that children go in because it might leave a bad impression on them and another thing, children might stay running around and touching things and the SCBU is not that kind of place, so I prefer that children even my son do not enter."

From these findings it is evident that the parents' views about visiting by siblings varied and this issue may warrant further investigation prior to attempting changes in the current policy. According to the family systems theory, siblings are elements of the family system and the interaction between all elements in the system is considered important to family functioning and it seems appropriate that this should also be considered when considering change in sibling visitation in SCBU.
4.2.6.3 Visiting by relatives

Parents’ discussions about visiting in SCBU culminated in the visiting by relatives. This is where the interactions between the nuclear family and the extended family became evident in this study. All parents agreed that relatives should visit the babies from behind the viewing glass and not directly next to the baby.

“...nahseb jien dak id-daqat ta’ babies u hekk ahjar jiġu minn wara l-hżeq fil-opinjoni tiegħi...nahseb li ha jolqtu l-magni...inti tkun qiesek ghandek xi haga taċ-ċaqquf dak il-hin tiebża.” (Joe Borg int 1 pg 7 line 20)

“...I think that with that size of babies and so on it is better that they come from behind the viewing glass in my opinion...you think they are going to hit the equipment...and for you it is like you have something made of china and you are afraid at that time.”

“...le li jidhlu direttament le ma toghġobnix...ha nghidlek allavolja l-familja tiegħek dak il-hin ħsiebu biex jara l-baby mhux għax hu marid...u hemm babies oħra wkoll u forsi l-każ tagħna ma kienx daqshekk imma trid iġġib rispett għal kulhadd.” (Mary Agius int 3 pg 11 line 18)

“...no I do not like it that they go in directly...let me tell you even if it is your family at that time one thinks of seeing the baby not that he is sick...and there are other babies as well and maybe in our case it was not so bad but you have to respect others.”

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However, all parents in this study expressed that the visiting policy allowed relatives to visit too little, for an hour only on a Sunday. In fact most parents even gave suggestions as to how the current policy may be improved. They mainly suggested longer visiting for relatives and more frequent not just on one day of the week.

“...ljista forsi jkun hemm a longer visiting period ghar-relatives, jew iktar frequent mhux just one day.” (Paul Vella int 2 pg 12 line 29)

“...maybe there can be a longer visiting period for relatives, or more frequent not just one day.”

“...bhan-nanniet jinkwetaw hafna...imqar ikunu jistghu jarawhom anke fust il-ğimgha, din telghet il-Hadd filghaxija u ghamlu ġimgha ma rawha xejn ghax ġriet hekk, per ezempju jkun hemm siegha kuljum.” (Ruth Spiteri int 4 pg 5 line 5)

“...grandparents worry a lot...at least they would be able to see them even during the week, she went up on Sunday evening and they spent a week without seeing her, because it happened like that, for example there could be an hour everyday.”

Since all parents in the study seem to have agreed on increasing the time available for relatives to visit, it appears that changing this aspect of the visiting policy is worth considering if a more family-centered approach is to be implemented. Nonetheless, results also indicated that relatives may not have visited the baby on admission although this is allowed by the visiting policy. It was not clear in the parents’ accounts whether this did not occur because relatives were unable to visit at the time of admission or else because they were unaware that the relatives could visit on
admission. Whatever the reason, the results help to draw the attention of the staff to inform parents that relatives can visit on the child’s admission.

Some parents also discussed the role of relatives as providing them with support during this experience. The parents’ families were considered as having provided them with support during this experience. Only one mother specifically mentioned the grandparents and made particular reference to her own mother as having provided her with most support. Although this latter finding is similar to what McHaffie (1992) found in her study when exploring the issue of grandparents as providing support to the parents however it is difficult to make comparisons with the present study since it was not clear whether the other parents were referring to the grandparents when they mentioned having had their families’ support. Yet, such findings give an indication of the ‘emotional cutoff’ of the parents from their family of origin which is a concept of the family systems theory. This refers to the parents’ ability to separate themselves from their own families (Casey, 1996). Having identified their own families as having provided them with support during their experience in SCBU, parents have shown that the emotional contact with their own families makes a larger contribution to the family’s interaction with the extended family (Comella, 1999).

“...ż-tifla ċrid thalliha ma xi hadd, ..... fl-istess hina it-tifla ma ridniex naqtughba barra allura l-familja importanti ghas-support.” (Mark Agius int 3 pg 22 line 8)

“....you have to leave the daughter with someone, at the same time we did not want to lack in attention to our daughter so the family is very important for support.”
“...le support kellna, kelli support minnu (ir-raqel) imbaghad mill-ġenituri taghna, per ezempju l-mummy kienet il-hin kollu kwazi kienet tiġi, ġejja u sejra kienet, l-iktar hi imbaghad kien hemm omm ir-raqel, missieri...” (Ruth Spiteri int 4 pg 12 line 21)

“...no we had support, I had support from him (my husband) then from our parents for example my mum was all the time coming and going, mostly it was her then there was my husband’s mother, my father..”

Parents also expressed how in the absence of one of the parents in SCBU, another relative or anyone who the parents choose, could have provided them with support if they had been allowed to visit with the visiting parent. This is in accordance with what Griffin (1998) suggests when saying that parents should be allowed to define their own support persons and decide who can visit their infant.

“...jiena nghid ghatija l-ahhar ġurnata r-raqel kien xogholl, ma setghax ikun mieghi, per ezempju kieku kien hemm l-mummy mieghi kont inhosni hafna ahjar...tghid tkun tnajn xolta, jiena u ommi per ezempju jew jien u ommu, jekk hu ma jkunx jista’ jiği, jew inkella per ezempju hin minnhom jien kont ghadni isfel (postnatal) kien hemm hu biss l-ewwel ġurnata speci tghid dahlet il-mummy tieghi jew il-mummy tiegħu ghax jien ma stajtx immur.” (Ruth Spiteri int 4 pg 5 line 17)

“....for me I can say that the last day my husband was at work, he could not be with me, for example if there was my mother with me I would have felt much better...you would still be two, me and my mother for example or me and his mother, if he could not come, or else for example at one time I was still
downstairs (postnatal) there was only him the first day, maybe my mother could go in or his mother because I could not go.”

“...bhala support...jien naqbel li jkun hemm persuna li m'ghandiex ghalfeju tkun tal-familja.” (Mark Agius int 3 pg 13 line 6)

“...for support...I agree that there would be another person not necessarily a family member.”

It is evident from this study's findings that various visitation issues and the current visiting policy are worthy of further investigation. Yet, this study has provided parents with the opportunity to voice their views as a result of their experience in SCBU which can be considered as an initial step to implement changes to meet the needs of families in the light of providing family-centered care.

4.3 Conclusion

The findings of this study suggest that the parents’ experiences in SCBU have highlighted various issues which are highly relevant when providing family-centered care. Such issues which have been grouped into themes and sub-themes, indicate that parents experience various reactions to their child’s hospitalization in SCBU, which reactions have been shown to be influenced by various demographic issues and also that reactions change over the child’s course of hospitalization. Parents’ participation issues as in the themes: caring for baby, barriers to child care and bonding with baby, have been shown to vary according to the baby’s stage of hospitalization with
differences between mothers' and fathers' participation being explored. Parents have also identified various issues which they feel hindered their participation in care in SCBU and also discussed how their experience influenced bonding with their baby. The next theme which was explored related to staff behaviours and attitudes which were extensively discussed by the parents in the study and this related namely to the parents' information and participation needs. Next, visitation issues were discussed by the parents and the timings and duration of their visits were explored. Aspects of the local visiting policy have also been discussed namely: the timings available for visiting by the parents and visiting by siblings and other relatives, with parents offering various suggestions how to improve the current policy. These study findings give an indication of the nature and extent to which aspects of family-centered care are currently being practised and experienced by parents in the local SCBU, with areas which require improvement being identified.
CHAPTER 5

CONCLUSIONS,
LIMITATIONS
AND
RECOMMENDATIONS
5.1 Conclusions

The aim of this study was to explore parents’ experiences of their participation and involvement in the care of their newborn in the local Special Care Baby Unit (SCBU). Whilst meeting this aim, this study served to identify the nature and extent to which characteristics associated with family-centered care are being practised and experienced by parents whose newborn required neonatal intensive care. An interpretive phenomenological research design was used and data was collected through semi-structured interviews with six couples which were recorded, transcribed and analysed using interpretative phenomenological analysis. Six major themes emerged from this analysis which included: reactions to SCBU, caring for baby, barriers to child care, bonding with baby, staff behaviours and attitudes, and visiting the baby.

Parents’ reactions to SCBU hospitalization have been shown to be negative in the initial stage of hospitalization and included reactions of shock, helplessness, fear and worry. However, it became evident that as the child’s condition improved, parents recalled more positive reactions, namely: being less worried and building up courage. Parents’ care to the baby included an exploration of the care-giving activities parents engaged in while in SCBU and it became evident that in the initial stages care-giving by the parents was limited to looking at and stroking the baby. As the child’s condition improved, more direct care was given by the parents, especially by the mothers, as in feeding, nappy changing and baby bathing, and holding the baby. It appeared that most parents, particularly the mothers felt a need to be directly involved
in hands-on activities and welcomed the opportunity to care for their babies. Parents considered that the procedures and equipment attached to their babies, particularly in the initial stages, acted as barriers to their participation in care. Being afraid and feeling physically unfit especially after having a caesarean section were also considered to hinder their participation. Parents in this study also felt that the separation from their newborn and their SCBU experience had a negative influence on their bonding with the child particularly initially when they had the least contact with their baby.

Staff behaviours and attitudes were found to have considerable influence on the parents' experiences as staff played a major role in providing parents with information and participation needs in SCBU. Various differences in staff behaviours and attitudes were noted by the parents in this study, with some staff being more supportive, approachable, helpful and encouraging parents' participation than others. Parents' visitation in SCBU revealed that the mode of delivery influenced the parents, particularly the mothers' visiting in the first few days after delivery. Having a caesarean section inhibited the mothers' visiting at this time while the fathers visited the baby. As the mothers were feeling better, parents started visiting the baby more, however if the father returned to work soon after birth his visiting was limited. The local visitation policy was extensively discussed by the parents and it became evident that they agree that parents only should visit directly next to the baby. However, it was suggested that the timings available for visiting should be improved. Some parents agreed that siblings should be allowed to visit in SCBU, however others did not agree to this. The issue of visiting by relatives indicated that parents agree that their relatives should be allowed to visit more often
and for a longer period but from behind the viewing glass not directly next to the baby. Some parents also discussed the supporting role their relatives provided during their experience. As an outcome of this study’s findings, recommendations for further research and implications for practice are discussed at the end of this chapter.

5.2 Limitations

Being a novice researcher using interpretative phenomenology for the first time, may be considered a limitation to this study, although discussions with the research supervisor throughout the research process helped identify problems at the outset and ensure adherence to the research process according to the chosen research design as much as possible.

The small sample size used in this study does not allow for generalization of the results to the whole population of parents who had an experience in SCBU with their newborn. Yet, such generalizations are not intended in interpretative phenomenology and the sample size used is considered appropriate in such a research design. Since parents were invited to participate in the study when they were approaching discharge but still in SCBU, can be viewed as a limitation since this might have indirectly influenced them to accept more readily to participate. Purposive sampling is considered to be prone to researcher bias, although this sampling method is acceptable in interpretative phenomenology.
Interviews allowed access to a small sample and lacked anonymity. Bias in the researcher’s interpretation and respondents’ response bias may have occurred. Respondents could have distorted their responses to become more socially desirable particularly since their anonymity was not possible. Also, interviews were considered costly in terms of time and energy, in organizing and traveling to the interviews and the length of the interview itself.

In spite of these limitations, the information obtained through this study helped to gain insight into the parents’ experiences of family-centered care as is currently being practised in the local SCBU. Recommendations for further research and implications for practice are suggested from the data obtained in this study.

5.3 Recommendations

5.3.1 Recommendations for research

- The themes which emerged in this study could be used to carry out quantitative research and the views of a larger sample of parents would be obtained.

- This study could be repeated to include different gestational ages of infants cared for in SCBU, with infants having more serious conditions and also with those requiring longer hospitalization in SCBU.
Further research could be carried out and include the perceptions about family-centered care of the staff working in SCBU, including midwives, nurses and paediatricians.

5.3.2 Implications for practice

- Staff attitudes and behaviours need to be family-centered and appropriate training to help develop such attitudes and behaviours could be provided as in post registration courses.

- Education to nursing, midwifery and medical students could include training in giving family-centered care.

- The current visitation policy (appendix G) in SCBU could be revised to be more family-centered.

- Improvements in the SCBU environment could be carried out in order that it becomes more supportive to family-centered care, which changes would allow more privacy and comfort for parents.

- Parents’ identified barriers to their participation in care and their interaction with their newborn should be examined and changes implemented to avoid such barriers as much as possible.
- The data from this study and also from further research could be used to devise a family-centered care policy which is specific to the local setting and which would help guide practice.
CHAPTER 6

REFERENCE LIST


APPENDICES
APPENDIX A

ELEMENTS OF FAMILY-CENTERED CARE
Elements of Family-centered care

(Rushton, 1990)

1. Recognition that the family is the constant in the child’s life while the service systems and personnel within those systems fluctuate

2. Facilitation of parent/professional collaboration at all levels of health care

3. Sharing unbiased and complete information with parents about their child’s care on an ongoing basis in an appropriate and supportive manner

4. Implementation of appropriate policies and programs that are comprehensive and provide emotional and financial support to meet the needs of families

5. Recognition of family strengths and individuality and respect for different methods of coping

6. Understanding and incorporating of the developmental and emotional needs of infants, children and adolescents and their families into health-care delivery systems

7. Encouragement and facilitation of parent-to-parent support

8. Assurance that the design of health-care delivery systems is flexible, accessible and responsive to family needs
APPENDIX B

PERMISSION LETTER FOR STUDY
Dr Simon Attard Montalto
Chairman Paediatrics
Paediatric Department SLH

3rd May 2005

Dear Sir,

I am a midwife working in the Special Care Baby Unit and I am currently studying for a Masters degree in Health Science (Midwifery), which requires me to carry out a research study. I intend to conduct a study entitled ‘Parents’ experiences of family-centered care in the SCBU’. Thus, I need to recruit parents of infants admitted to the unit and interview them following the infant’s discharge home. Hence, I would like to ask your permission so I will be able to invite parents having their baby in SCBU to participate in this study in the next few months. I would appreciate a reply by the 14th May 2005, due to an upcoming deadline.

Thank you

Yours truly,

Rita Pace Parascandalo
Midwife - SCBU
TO WHOM IT MAY CONCERN

Dear Sir/Madam,

RE: Master Degree in Health Science (Midwifery)
APPLICATION: Ms. Rita Pace Parascandalo

I am writing to support Ms Pace Parascandalo’s proposal for a research project as part of her Master’s Degree in Health Science. I have no reservations with her proposal and, indeed, would strongly support this study.

Yours sincerely,

[Signature]

DR. S. ATTARD MONTALTO
Chairman Paediatrics

MINISTRY OF HEALTH - MINISTERU TAS-SAHHA
APPENDIX C

COVERING LETTER AND CONSENT
16th May, 2005

Dear parents,

I am a qualified midwife and in partial fulfillment of my Masters degree in Health Science (Midwifery), at the University of Malta, I am carrying out a research project about the parents' experiences of family-centered care in the special care baby unit. It is anticipated that the findings of this study would help improve the service provided in our unit.

Since you possess the criteria set for participation in this study, you are being invited to participate in three interviews at your own convenience and at your own home, unless you prefer otherwise. The interviews would be tape-recorded and should take about thirty to forty-five minutes. Your participation is on voluntary basis and have a right to refuse at any time. However your co-operation in participating in this study would be greatly appreciated. All information you provide will be kept confidential and used only for the purpose of the study. Your identity will not be revealed as names will be changed, thus your anonymity will be maintained. On completion of the study the tapes will be destroyed. Should you agree to participate in this study please sign below.

Yours sincerely,

Rita Pace Parascandalo
Midwife

We have read and understood the above details regarding this research and agree to take part in this study.

Mother's signature ______________ Father's signature ______________

Mother's name ________________ Father's name ________________
APPENDIX D

DEMOGRAPHIC DATA FORM
Demographic data form

Name of mother: ..................................................

Name of father: ..................................................

Gestation at time of delivery: ..................................

Mode of delivery: .............................................

Age of baby at time of admission: ..........................

Reason for SCBU admission: .................................

Length of stay in SCBU: ....................................

Previous SCBU experience: Yes....... No........

Number of siblings: .........................................
APPENDIX E
INTERVIEW SCHEDULE
**Interview Schedule**

**English**

1. What can you tell me about your experience in the SCBU?
   Probes: your care to the baby?
   mother/father differences?

2. What was your experience like with the midwives and nurses?

3. What about your presence at SCBU during your child’s hospitalization?
   Probes: other family members?

4. What are your thoughts and feelings about this experience?
   Probes: on admission and throughout SCBU hospitalization?

Would you like to add anything about this experience?

**Malti**

1. X’tgiduli dwar l-esperjenza taghkom fl-SCBU?
   - kif hadtu hsieb it-tarbijja?
   - differenzi bejn l-omm u l-missier?

2. Kif kienet l-esperjenza taghkom mal-midwives u n-nurses?

3. X’tgiduli dwar il-preżenza taghkom l-SCBU waqt li t-tarbijja kienet hemm?
   - membri ohra tal-familja?

4. X’inhuma l-hsibijiet u s-sentimenti taghkom dwar din l-esperjenza?
   - meta dahlet it-tarbijja u waqt li kienet l-SCBU?

Tixtiequ żżidu xi haga ohra dwar din l-esperjenza?
APPENDIX F
FURTHER EXAMPLES OF
VERBATIM QUOTATIONS
Further examples of verbatim quotations from parents’ interviews relevant to each theme and sub-themes.

1. Reactions to SCBU

“...ghidt mela ghandu xi haga, bhal speci cesarean ma tistax timxi mill-ewwel, ghidt mela ghandu xi haga ma jridux jghiduli....” (Julie Muscat int 6, line 8)

“I said he must have something, after a cesarean you cannot walk immediately, I said he must have something then and they do not want to tell me.....”

“.....inti assolutament qieg hed at the mercy of whoever there might be ghax at the end of the day ma tista’ taghmel xejn inti hlief tistaqsi.” (Brian Muscat, int 6 pg. 10 line 13).

“.....you are absolutely at the mercy of whoever there might be because at the end of the day you cannot do anything accept for asking.”

“.....wara l-initial shock qiesek tipprova tahseb u tirraguna, on personal basis hassejtha diffici kif ser nispega lill-mara li t-tarbija ser ikollha titla’ l-SCBU, iżjed u iżjed meta l-mara kienet ghada ma setghetx tara t-tarbija minhabba li kienet cesarean u kienet ghadha mbiex qieg hed a f’taghha ghal kollox u fl-ahhar il-biza li jista jkun hemm xi haga tibqa ghaddejia ġo mohħok il-hin kollu, bażikament dik l-iktar haga li ddejjqek.....” (Brian Muscat int 6, pg 3 line 5)

“.....after the initial shock you try to think and reason, on personal basis I found it difficult to explain to my wife that the baby needed to be taken to SCBU, even
more so when she had not yet seen the baby because she had a cesarean and had not come round yet and finally the fear that something is wrong lingers on in your head all the time, that is basically the thing that bothers you most.....”

“ma bqajtx ninkwieta daqshekk ghax jien bdejt narah, imma hi le.” (Paul Vella, int 2 pg. 4 line 24)

“I did not continue to worry so much because I could see him, but she could not.”

“jiena bqajt impressionata ghax qatt ma dhalt go ward hekk, tara dawk il-magni, il-babies go l-inkubaturi, taqbdek hlewwa ta’qalb.” (Ruth Spiteri, int 4 pg. 3 line 23)

“I was impressed because I had never entered such a ward, you see those machines, the babies in incubators, you feel swoon.”

“...qiesu wara jumejn, tlieta serrahna rasna...” (Ruth Spiteri, int 4 pg 7 line 22)

“...after two, three days our minds were at rest...”

2. Caring for baby

“...kont noqghod bil-qieghda hdejh, jiftulek it-twieqi ta’ l-inkubatur u nmisslu naqra jdejh...” (Julie Muscat int 6 pg 4 line 31)

“...I used to sit next to him, they open the portholes of the incubator and I used to stroke his hand...”
“...jiena kont nerfaghha u kont nghin lilha (lill-mara) biex.tbiddilha u tahlilha...” 

(Anton Spiteri int 4 pg 2 line 12)

“... I used to hold her and help her (his wife) to wash her and change her...”

3. Barriers to child care

“...ma tantx stajna ghax daqqa bis-CPAP, daqqa bid-drip gozż-zokra....ma stajniex nerfughha” (James Mifsud int 5 pg 4 line 17)

“...we could not do much because she was sometimes with CPAP, sometimes with the umbilical line...we could not hold her.”

4. Bonding with baby

“...li ghandek li ma tkunx il-hin kollu hdejk...” (Ruth Spiteri int 4 pg 13 line 17)

“...the thing is that she is not next to you all the time...”

“...jien erfajtha żewġ sekondi u ma rajthiex iżjed...” (Diane Mifsud int 5 pg 2 line 19)

“...I held her for two seconds and did not see her anymore ...”

“...qiesek ghandek oġġett fuq television, qed tarah imma ma tistax tmissu...” 

(James Mifsud pg 13 line 23)

“...it is like having something on television, you can see it but you cannot touch it...”
“... ikollok inqas kuntatt mal-baby meta hu qieghed hemm (l-SCBU)...” (Julie Muscat pg 27 line 7)
“...you have less contact with the baby when he is there (in SCBU)...

“...kieku ma ġewx jaghtubuli f’idejja ma kontx ser immissu il-baby...ghax ma tkunx qiesek trid torbot qalbek mieghu f’każ li jiġri xi ħaġa...” (Sue Vella int 2 pg 4 line 29)
“...I would not have touched the baby if they had not come and put him in my arms...because it is like you do not want to become attached to him in case anything happens...

“...dan l-iktar li domt ma bondjajt mieghu (mit-tfal l-ohra) jien onestament minhabba din l-esperjenza,...tant bżajt li anqas ridt nibbondja.” (Sue Vella int 2 pg 10 line 8)
“...it took me the longest to bond with this child (from the other children) to be honest because of this experience... I was so afraid that I did not want to bond.”

“...hemmhekk fit li xejn kelli bond mieghu...kelli ċertu bża li ser jiġrilu xi ħaġa meta kien f’idejja.” (Julie Muscat int 6 pg 17 line 3)
“...I had very little bond with him there...I had a certain fear that something might happen to him when he was in my arms.”
5. Staff behaviours and attitudes

- Need for information

“...kif kont nidhol (l-SCBU) dejjem kont insaqsi min qed jiebu hsieb il-baby tiegh.” (Brian Muscat int 6 pg 8 line 6)

“...when I used to enter (SCBU) I always used to ask who is taking care of my baby.”

“...meta kont incempel bil-lejl, huma kienu jghiduli baqa tajeb bhal ma kien, which was good enough for me.” (Brian Muscat int 6 pg 11 line 17)

“...when I used to phone during the night, they used to tell me that he remained alright as he was, which was good enough for me.”

“...kien hemm wahda npressjonatni, vera ghamlitilha kuragg...l-iktar wahda li kompiolet maghna....qiesba kienet differenti minn haddiehor.” (James Mifsud int 5 pg 20 line 8)

“...there was one who really impressed me, she really encouraged us...she gave us the most attention...it was like she was different from the others.”

“...dejjem trid tkun taf iżjed, kieku sibt persuna spjegatli iktar fid-dettal dejjem aħjar ....anke l-equipment tista’ dak li jkun tispjegalu ghaliex qieghed.” (Anton Spiteri int 4 pg 6)
“...you always want to know more, if I found someone who explained to me in more detail it would have been better...even the equipment one can explain what it is there for.”

“...minghajr ma trid ikun hemm persuna forsi tista’ tolqtok aktar minn haddiehor...per ezempju darba minnhom kien hemm nurse jew midwife, apprezzajt hafna gabet is-sigju hdejna u qaghdet tfehmena, vera rajtha gentili u hadt pjačir hafna biha, dik li tara li qed taghtik attenzjoni personali u you are not just a number, dik tajba hafna.” (Brian Muscat int 6 pg 8 line 10)

“...without wanting to there would be a person who attracts you more than an other...for example once there was a nurse or midwife, I really appreciated that she got a chair next to us and she was explaining, I really think she was gentle and I was really happy with her, seeing that you are given that personal attention and you are not just a number, that is really good.”

“Xi haq li jiena ghogbitni kienet li wara li jsir ir-round tilghodu mit-tobba t’hemmhekk kienu jaghtuna ċ-cans li titkellem mal-paediatrician dak il-hin u tistaqli li ghandek bżonn u ovvjament kienu jirrisponduna, fit-tlett ijiem li ghamel hemmhekk kull darba gew ikellmuna.” (Brian Muscat int 6 pg 9 line 9)

“Something that I liked was that after the ward round in the morning the doctors there used to allow us to talk to the paediatrician at that time and you ask what you want and obviously they used to answer us, in the three days he was there they always came to speak to us.”
“...hemmhekk l-istaff ghandhom xi haga specjali... anke jarawk down jiġu jiaptptulek fuq daharek...” (Mary Agius int 3 pg 6 line15)

“...the staff there have something special...even if they see you down they come and give you a pat on the shoulder....”

“Nahseb l-istaff huma vera vera dedikati.” (Brian Muscat int 6 pg 4 line 12)

“I think the staff are really really dedicated.”

- Need to care for baby

“....rigward breasfeeding, jiena kont diża qed nahseb li kif nigi d-dar ser nieqaf, bdejt nibża li ġie dehydrated ghalhekk u ghidt kif immur d-dar nieqaf...minn hemmhekk li komplejt...kienu jiempluli anke bil-lejli biex nitla ntieb breastfeeding, kienu jaqghodu mieghi...” (Jane Borg int 1 page 10 line 17)

“....about breastfeeding, I was already thinking that once I come home I stop, I was afraid that he became dehydrated because of that and I said when I go home I stop...it was from there that I continued...they used to phone me even at night to go and breastfeed him, they used to stay with me...”

“...urewni kif inbibdililha u kif nahsilha....” (Ruth Spiteri int 4 pg 3 line 6)

“...they showed me how to change her and bathe her...”

“...anke għall-feed ihajruk, isaqsuk tridx tisgieha inti...” (Ruth Spiteri int 4 pg 8 line 9)

“...even for the feed they encourage you, they ask you if you want to feed her...”
“... hrjigt minn hemm bla biża mhux dik il-biża li rrid nihhandilja baby u ma nafx x‘irrid naghmel.” (Ruth Spiteri int 4 pg 8 line 5)

“...I went out of there without fear, not afraid of having to handle a baby and not knowing what to do.”

6. Visiting the baby

- Parents’ visiting

“... għall-bidu kont nitla jien biss għax hi ma setghetx titla.” (Paul Vella int 2 pg 4 line 15)

“...initially only I used to go because she could not go up.”

“Peress li hlist ċesarja l-ewwel jumejn ma stajtx nitla...” (Mary Agius int 3 pg 2 line 30)

“Since I delivered by cesarean section I could not go the first two days...”

“Kont naghmel ħafna ħin, l-iktar l-iktar kont ninżel norqod fitt, niekol xi haġa u nerga nitla... (Ruth Spiteri int 4 pg 4 line 19)”

“I used to spend a lot of time there, at most at most I used to go down to sleep a little, eat something and go up again...”

“Anqas naf kif kien jghaddi l-ħin, tarah twil mill-ħdax sas-sitta, kont forsi ninżel niekol, anqas nistrieh, kont nekspressja l-ħalib u nerga nnur.” (Sue Vella int 2 pg 8 line 23)
"I do not know how time used to go by, you would see it long from eleven till six, I used to go down to eat maybe, not even rest, express breastmilk and go again."

"...mill-hdax sas-sitta qed nitkellmu seven hours straight which I think is reasonable." (Paul Vella int 2 pg 13 line 18)

"...from eleven till six we are saying seven hours straight which I think is reasonable."

"...irrangajt ix-xoghol minflok afternoon kont nidhol filghodu imma dan mhux kulhadd jista' jirranga li stataf naghmel jien." (James Mifsud int 5 pg 21 line 7)

"...I arranged at work that instead of afternoon I go in morning but not everyone could manage such arrangements as I could do."

"Jiena nahseb ghandu jkun hemm anke ċertu hin bil-lejl ...jekk il-ġenituri jixtiequ jmorru jaraw il-baby." (James Mifsud int 5 pg 17 line 1)

"I think there should be a certain time even at night...if the parents wish to go and see the baby."

- Visiting by siblings

"...xtaqtu ġabu mieghu l-ewwel ġumata (lit-tifel l-iehor)....kelli nistenna biex nohroġ anke jien biex narah ghax imbaghad Sunday ġabu mieghu u mora d-dar. Kien ilu jsqsi ghalija hamest ijiem." (Julie Muscat int 6 pg 15 line 15)
“...I wish he had got him the first day (my other son)...I had to wait to be discharged even I to see him because then on Sunday he got him and we went home. He had been asking for me for five days.”

“...ghax hu (it-tifel l-iehor) parti mill-familja.” (Julie Muscat int 6 pg 26 line 26)
“...because he (my other son) is part of the family.”

“...kieu mqar it-tifla setghet tarah ftit kuljum minn wara l-hgieg...le mhux li tidhol hemmhekk...kieku tajeb kont niehu pjaċir ghax hi x’inh ohtu...” (Mary Agius int 3 pg 17 line 1)
“...if only my daughter could see him a little every day from behind the viewing glass...no not that she goes inside...that would be good I would have liked it because after all she is his sister...”

- Visiting by relatives

“...dik tal-Hadd rajtha ftit wisq siegha, jew inkella tghid minflok il-Hadd biss, tghid l-Erbgha u l-Hadd, ikun hemm darbtejn f’gimgha minflok darba...” (Diane Mifsud int 5 pg 9 line 25)
“...on a Sunday one hour is too little, or else instead of Sunday only, say Wednesday and Sunday, there would be twice a week instead of once...”

“....li Sunday biss jistghu jarawhom minn wara l-hgieg, nahseb hi naqra iebsa u siegha, siegha halli nhalluba imma kieku minflok just on a Sunday nżieda jekk hu possibile, basta minn wara l-hgieg....imbaghad trid tiftakar wahda.... jkun hemm
min fortunatament bhalna thank God ghamilna three days biss imma li kicku
dawk it-three days kienu per ezempju Tuesday, Wednesday u Thursday, in-
nanniet ma kienux jistghu jitilghu jarawh, it had to be on a Sunday.” (Brian
Muscat int 6 pg 13 line 20)

“....that they could only see them on a Sunday from behind the viewing glass, I
think it is a bit hard just an hour, leave it an hour but instead of on a Sunday I
would increase it, if possible, as long as from behind the viewing glass...than you
have to remember one thing...there are those like us who fortunately thank God
stayed three days only but if those three days were for example Tuesday,
Wednesday and Thursday, the grandparents would not have been able to go and
see him, it had to be on a Sunday.”

“...jekk idum il-baby u forsi l-missier imur lura ghax-xoghol, tkun tajjeb li
mbaghad jista’ jidhol xi hadd iebo...u hekk xorta jkunu tnejn.” (Jane Borg int 1
pg 12 line 13)

“...if the baby stays long and maybe the father returns back to work, it would be
good then that someone else can go in....and like that they would still be two.”
APPENDIX G

SCBU VISITING POLICY
Special Care Baby Unit

Visiting Policy

The SCBU staff understand and are very supportive to parents whose babies are being cared for at the SCBU. The unit Policy recommends and encourages regular parents visiting that would enhance parents’ reassurance on their infants’ well-being.

Parental visiting is open between 11.00am and 6.00pm daily and on admission. Out of schedule visiting arrangements may be done with postnatal staff for parents to visit their critically ill baby or when doctors need to speak to parents on their infants’ condition.

The SCBU staff are committed to abide with the Breastfeeding Policy and allow breastfeeding mothers to visit and directly breastfeed their infants on demand 24 hours a day. During the morning postnatal staff will phone to make arrangements for breastfeeding mothers visiting at 8.00am. During the nights SCBU staff will call at postnatal when the baby is crying for feeds to inform the mother re breastfeeding.

However it might become necessary that parents may be asked to wait outside the unit during an emergency e.g. an admission, during ward rounds and during any procedure.

Single mothers may be accompanied by their partner or by ONE close relative that would support the mother during these stressful times when their babies are at the SCBU.

The unit Visiting Policy supports the relatives right to visit as they could be very supportive to parents. Thus other relatives and siblings are allowed to visit, two at a time, accompanied by both or either of parents on admission and every Sunday between 3.45pm and 4.45pm from behind the viewing glass. It is important that for the benefit of the vulnerable infants that any sick relative should feel responsible not to visit.

Updated 5.4.04