Parents’ experiences following the discharge home of their premature infant

by

Diana Borg

June 2006
To my beloved husband

and

to my wonderful family
DECLARATION

I declare that the dissertation is entirely my own work, carried out as part of a Master’s Degree in Health Science Nursing at the Institute of Health Care, University of Malta

Diana Borg
B.Sc (Hons) Nursing

June 2006
ACKNOWLEDGEMENTS

First of all I would like to thank my supervisor, Ms. Rita Borg Xuereb for her critical yet supportive supervision. She has wisely and patiently guided me through the difficulties of such a study.

I would like to express my gratitude to all the parents who participated in my study and shared their experiences with me, since they were the basis of my study. Thank you for all the information you have given me and for the time you have spared to share this experience.

I have received invaluable help from my uncle Mr. Charles Casha, a Maltese lecturer and writer who helped me with the translations of the interview schedule, consent form and excerpts from the transcripts.

I want to devote my dearest thanks to my friends and my family, my mother Rose, my father Joseph and my sister Leona, who have patiently supported me during the high and low moods of this study, but most of all I would like to thank my beloved husband Matthew for his patience, support and love throughout, his support was invaluable.

Thanks

Diana Borg
ABSTRACT

The purpose of this study was to gain a deeper understanding of parents’ experiences following the discharge of their premature infants from hospital. An interpretive phenomenological approach was used to explore these experiences so as to gain an insight and an understanding of the parents’ reality and experience. The participants consisted of a criterion sample of six couples who had a premature infant at the local Special Care Baby Unit. The data was collected, after the infant’s discharge from hospital at the participants’ home, by means of semi structure interviews, and then it was transcribed and analyzed thematically.

Nine main themes emerged from the study, these were “Impact of the Special Care Baby Unit”, “Loneliness”, “Going home”, “Tiredness”, “Coping at home”, “Knowing the baby”, “Education and Practice” “Support” and “The baby’s well being”. Through this study it was found that although the education given prior to discharge was effective, there is still the need for a protocol regarding discharge planning as well as the need for staff training in this aspect, since the discharge planning received from the parents in this study was not consistent. The establishment of a follow up care service for all infants discharged from the Special Care Unit might also be of importance in helping parents cope with the transition from hospital to home.

Further research also needs to address both parents’ experience of the Special Care Baby Unit locally, since from this study it was found that the experiences parents have there are unforgettable and very important to them. A quantitative study needs also to be done exploring the data obtained from this study so as to look at this aspect more holistically, as well as making the results more generisable. More research could also be done exploring the Special Care Baby Unit staff’s experiences of discharge planning, so as to gain their perspective in this aspect.
# TABLE OF CONTENTS

1 Introduction 10

2 Literature Review 12

2.1 Introduction 12

2.2 Developmental Outcomes of premature infants 14

2.2.1 Medical Problems 14

2.2.2 Psychological and Social Problems 15

2.2.3 The effect of the parent-infant interaction on infant development 16

2.3 Theoretical Framework: Roy’s adaptation model 19

2.3.1 Modes in Roy’s model 19

2.4 Parents experience of having a premature infant 27

2.5 Parents’ experiences when their premature infant is discharged from hospital 29

2.6 Discharge Planning 42

2.7 Follow up Care 45

2.8 Conclusion 49

3 Methodology 52

3.1 Aim of the Study 52

3.2 Research Question 52

3.3 Operational Definitions 52

3.4 Research Approach 53

3.5 The Philosophy of Phenomenology 54

3.6 Research Design 56
3.7 Target Population and Sampling Techniques 57
3.8 Research Instrument 59
3.9 Pilot Study and Modifications 63
3.10 Evaluating the Research design 64
3.11 Limitations of the Research Design 66
3.12 Ethical Considerations 67
3.13 Interpretations of Data 69

4 Findings and Discussion 72
4.1 Introduction and Background Data 72
4.2 Themes 76
   4.2.1 “Impact of the Special Care Baby Unit” 76
   4.2.2 “Loneliness” 77
   4.2.3 “Going Home” 78
   4.2.4 “Tiredness” 85
   4.2.5 “Coping at home” 86
   4.2.6 “Knowing the baby” 88
   4.2.7 “Education and Practice” “ 89
   4.2.8 “Support” 97
   4.2.9 “Baby’s well being” 101

5 Conclusions 110
5.1 Limitations of the study 112
5.2 Implications for practice 113
5.3 Recommendations for research 114

Reference List 116
**LIST OF APPENDICES**

<table>
<thead>
<tr>
<th>Appendix</th>
<th>Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Appendix 1</td>
<td>Theoretical framework: Roy’s adaptation model</td>
<td>131</td>
</tr>
<tr>
<td>Appendix 2</td>
<td>Interview schedule (English)</td>
<td>144</td>
</tr>
<tr>
<td>Appendix 3</td>
<td>Covering letter and informed consent (English)</td>
<td>145</td>
</tr>
<tr>
<td>Appendix 4</td>
<td>Interview schedule (Maltese)</td>
<td>146</td>
</tr>
<tr>
<td>Appendix 5</td>
<td>Covering letter and informed consent (Maltese)</td>
<td>147</td>
</tr>
<tr>
<td>Appendix 6</td>
<td>Permission from the Director of Paediatrics</td>
<td>148</td>
</tr>
</tbody>
</table>
LIST OF TABLES

Table 2.4.1 Research studies concerning parental experience after the discharge of their premature infants home. 35

Table 2.4.2 Research studies concerning parental experience after the discharge of their premature infants home. 40

Table 4.2.1 Table of themes 73
INTRODUCTION

Prematurity refers to infants delivered before 37 completed weeks gestation, more than 400,000 premature infants are born each year in the United States, that is, 12.3% of all the live births (Martin, Hamilton, Sutton, Ventura, Menacker, & Munsom, 2005, Lau, 1998, Maroney, 2000). In 2004, in Malta out of the 3838 total births, 8% (300) were preterm births. (National Obstetric Information System, Malta, 2004). Due to advances in both medicine and technology, survival rates of these premature infants have increased dramatically (Kessenich, 2003). Thus implying that the number of parents caring for premature infants has also been on the increase and that additional care is being needed by these parents.

Premature birth is a risk factor for poor developmental outcomes, as well for increased health problems. Even if the prematurity is not severe the risks of developmental disabilities has been consistently documented in research (Blackburn, 1995, Kessenich, 2003). Coping with a premature birth is a stressful and difficult experience, but stress and anxiety were also found to be present after the infant has been discharged from hospital (Veddovi, Kenny, Gibson, Bowen & Starte, 2001, Charpak, Ruiz & Figueroa de Calume, 2001). However, preparation for discharge through education and practical experience of caring for their infant has been found to provide a smoother transition for the parents and make the discharge less traumatic (Wyly, 1995).
As a staff nurse working in the local Special Care Baby Unit (also known as the Neonatal Intensive Care Unit), I have always wondered what happened to the parents after their baby's discharge home. I was also concerned that the discharge preparation they received to cope with their infant's needs at home was somewhat incomplete. This inspired me to explore this area for my research study so as to assess the current situation, as well as to create an awareness of the parents' needs prior to discharge.

Few studies explored the effects of caring for a premature infant after hospital discharge and they mainly focused on the premature infant's mother. This also emphasized the need for further research in this area including both parents in the study. Furthermore, due to the uniqueness of the Maltese culture, a study exploring parental experience after their premature infant is discharged from hospital could provide salient information for local nursing practice. Though results from previous studies are helpful in giving a perception on this issue, they cannot give the insight on the Maltese parents' experience since they were conducted in different countries. Thus I decided to conduct a qualitative research study exploring the experience of parents, after their premature infant's discharge home. I chose an interpretive phenomenological approach so as to provide a real life understanding in the parents' reality and experience and the research question was "What is the lived experience of parents following the discharge of their premature infant home?"
CHAPTER 2: LITERATURE REVIEW

2.1 Introduction

Prematurity is believed to be caused by a number of factors such as maternal age, poor nutrition, smoking, poor maternal health and maternal low socioeconomic status (D’Alton & Grant, 1990 as cited in Lau, 1998). Due to technologic advances in the perinatal and neonatal care, survival rates for premature infants have improved dramatically (Falleiros Mello, Melo-Rocha, Scochi & Garcia-Lima, 2002, Hussey-Gardner, Wachtel & Viscardi, 1998, Kessenich, 2003, Trachtenbarg & Golemon, 1998, Veddovi, Kenny, Gibson, Bowen & Starte, 2001, York & Devoe, 2002). In 1991, the Victorian infant collaborative study group, reported a 68% survival rate in infants weighing 500 to 1250 grammes at birth (as cited in Hussey-Gardner et al, 1998).

In the present study the parents’ experiences when their premature infant is discharged from hospital will be explored. Due to the small number of phenomenological studies in this area, the findings from this study would be more valuable since the parents’ real life experiences will be discovered. This experience is obviously influenced by the fact that their infant was born prematurely. Coping with the premature birth can be a difficult and stressful experience for the parents. (Veddovi et al, 2001 refer to table 2.4.1). The emotional adjustment of the mother may be compromised and thus result in
negative consequences in the infant. The birth of an infant prematurely precipitates a crisis for the parents, thus forcing them to redefine and adjust their parental role, and the parent-infant relationship may be compromised (Haut, Peddicord, O'Brien, 1994). This was also shown in the phenomenological study that was conducted by Nyström and Axelsson, (2002). They explored the experiences of mothers being separated from their newborn infants when they were admitted in the Neonatal Intensive Care Unit. In this study narrative interviews were conducted with eight mothers one to two months postpartum regarding their experience of the separation from their infant after their infants’ discharge home. A thematic analysis was done and from the data it was found that their experiences had caused them emotional strain and anxiety. The problem with this study is that the data was collected after the experience had occurred and thus there may have been recollection bias where the mothers would not recall their exact feelings and experience. On the other hand it would not have been ethical to interview these mothers much earlier as they would have been too anxious about their baby’s condition, and having to participate in this study might have distressed them more.

Roy’s adaptation model (see Appendix no 1) was chosen as a theoretical framework in this study because it supports the promotion of adaptation and it explains how adaptive processes affect health (Akinsanya, 1994a and Fawcett, 1995). This nursing model will be used to give structure and a sense of conceptual
consistency to this research study, and also to give focus for the discussion as well as a basis for the findings (Tolson and McIntosh, 1995).

2.2 Developmental outcomes of premature infants

Premature birth is a risk factor for poor developmental outcomes (Blackburn, 1995, Tobey and Schraeder, 1990). Thus these increased survival rates have been associated with higher rates of health problems, developmental delays and the need for earlier intervention especially for the very small premature infants (Blackburn, 1995, Lee, Nor & Oh, 2005, Singer, Salvator, Guo, Collin, Lilien & Baley, 1999).

2.2.1 Medical Problems

Due to the advances in medical nursing care, many high risk infants are surviving the neonatal period with severe life threatening chronic illnesses (Miles, Holditch-Davis, Burchinal & Nelson, 1999, Miles & D’Auria, 1994). However, even if the prematurity is not very severe, research has consistently documented the risk of these preterm infants for developmentally disabilities (Bernbaum, 1994, Blackburn, 1995, Connors, 2003, Kessenich, 2003, Lee, et al, 2005 & Tobey and Schraeder, 1990). This deficit could be temporary and could be resolved during the first year of life, however subtle motor deficits may still persist and can later impact school performance (Carter, 2001).
Birth weight and gestational age are critical factors in determining these developmental outcomes, in fact the smallest and most immature infants have the greatest the risk status for motor deficits in the premature infant (Avon Premature Infant Project, 1998, Connor, 2003, York & Devoe, 2002). Infants born less than 750 grammes have a much higher risk for neuro-developmental problems (Hussey-Gardner et al, 1998). Infact a strong predictor for developing cerebral palsy later on in life, is a gestation of 32 weeks or less at birth (http://origins ofcerebralpalsy.com/14-bulletinboard.html). Other long term problems in these infants can include, chronic lung disease and vision and hearing impairments (Maroney, 2000, Haslam & Whaites, 2000,York & Devoe, 2002).

2.2.2 Psychological and Social Problems

Developmental problems can, not only be biological or medical in origin but can also be social environmental (Bacharach & Baumeister, 1995, Morawski Mew, Holditch-Davis, Belyea, Miles & Fishel, 2003). Children born prematurely exhibit learning and cognitive problems, these may be due to the Special care Baby Unit environment. These problems include language delays, visual motor difficulties and attentional deficits during the first few years of life (Kessenich, 2003). These are believed to be associated with later learning problems.

It is rather difficult to determine which infants will suffer from the consequences discussed above. Therefore specialized follow up examinations to detect any
motor or neurological delays are very important in the care of the premature infant after discharge (Connors- Lenke, 2003, Skellern, Rogers & O’Callaghan, 2001). The problems discussed could all impact on the parent’s adaptation process

2.2.3 The effect of the parent-infant interaction on infant development

Socioeconomic status, maternal age and the home environment have been considered to be critical factors in an infant’s development (Hummel, 2003). The infant’s development is also influenced by the mother’s early attitudes, which can lead to disturbances in the mother-infant relationship. This could lead to further developmental problems, since important associations have been discovered between the quality of the parent-infant relationship and the child’s developmental outcomes. Positive interactions within the first year of life have been linked with improved intellectual and language abilities (Avon Premature Infant Project, 1998, Langley, Hollis & Mac Gregor, 1999, Perlman, 2001).

In the quantitative study by Davis, Edwards & Mohay, (2003), a questionnaire and a 20 minute video tape showing a mother and child feeding interaction, was used for data collection to explore variables affecting the mother-infant interaction in premature infants. Sixty two mothers were involved in the study, they were asked to fill a questionnaire regarding their interaction with their baby and then were video taped whilst feeding their infant three months after they were
discharged from the Special Care Nursery. Results suggested that preterms are less responsive social partners, this might inhibit the formation of the parent-infant interaction. Effective coping strategies were also identified as helping in the formation of the parent-infant interaction, as mothers who utilized coping strategies were displaying better feeding scores with their infants. Limitations to this study include the short period of follow up which was 3 months and the use of video taping which might have made the participants self conscious and thus the interaction less real. This might have influenced how the mothers behaved with their baby and might not have shown a real life situation. Davis et al (2003) have suggested that although altering socioeconomic status and psychosocial variables may not be possible, the parent-infant relationship may be modifiable.

Difficulties to form this relationship were attributed to the long separation during the infant’s hospitalization, lack of responsiveness on the part of the infant and parental stress (Klaus & Kennel, 1982 as cited in VandenBerg, 1999). Another factor found to be detrimental to the mother-infant interaction was maternal depression. A description of the lived experience of maternal post partum depression was summarized from forty research articles, mainly being qualitative in nature, in the meta-analysis done by Beck (2003). It was stated that mothers with depression show less affection to their child, less response to infant cues and also withdraw from affectionate behaviour (Beck, 2003). In fact, infants of depressed mothers were found to be harder to please, more restless, make less positive facial expressions and vocalizations and tend to have more sleep

17
problems. They also tend to have behaviour problems, insecure attachment and
cognitive deficiencies (Beck, 2003). Though these findings are very useful, more
quantitative studies are needed to increase the generisability of these results since
in this meta-analysis qualitative studies were mainly used.

The parents’ early attitudes are also influenced by the birth of the premature
infant, which is a stressful event for the parents, and can cause feelings of anxiety,
worry, fear guilt, depression and helplessness (Holditch-Davis & Miles, 2000).
These feelings are further exacerbated due to the fact that these infants are at risk
for developmental disabilities (Bracht, Kandankery, Nodwell & Stade, 2002).
This was found in the qualitative study by Holditch-Davis and Miles (2000),
which explored mother’s neonatal intensive care experiences. Interviews were
conducted with thirty one mothers when their infants were six months of age
corrected for prematurity and were analysed by using the preterm parental distress
model as a conceptual framework. The analysis verified the presence in the data
of the six major sources of stress indicated in the Preterm Parental Distress
Model: 1: pre-existing and concurrent personal and family factors, 2: prenatal and
perinatal experiences, 3: infant illness, treatments, and appearance in the NICU, 4:
concerns about the infant’s outcomes, 5: loss of the parental role, and 6: health
care providers. The study results also indicate that health care providers,
especially nurses, can have a major role in reducing parental distress by
maintaining ongoing communication with parents and providing competent care
for their infants. However since data collection occurred some months after the
birth of the premature infant, recollection of the feelings experienced at that time might not be so accurate.

2.3 Theoretical Framework: Roy Adaptation Model

The present research focuses on how the parents' experience the birth of their premature infant, especially after the baby's discharge home from the Neonatal Intensive Care Unit. Thus, adaptation to these events is considered to be a crucial part of the study. Adaptation relates to the way a group or individual respond to changes in the environment (Akinsanya, 1994b). Roy develops this theme of adaptation and adapts it to nursing. This model uses an approach which focuses on individuals who may be experiencing difficulties in coping with the changes in their lives (Akinsanya, 1994b). In this case the change in the parents' life is considered to be the birth of their premature infants and their consequent discharge home. This model was considered to be ideal to adequately identify the stimuli leading to adaptive and maladaptive behaviours in these parents, as well as exploring their adaptation level (Hedberg, Nyqvist and Sjodén, 1993).

2.3.1 Modes in Roy's Model

The use of this model in the present study mainly focuses on the last three modes which are the self concept, role function and interdependence modes. These are
used to identify the factors causing the need for adaptation, as well as to identify how the parents in the study are adapting to the stimuli they are receiving.

The **self-concept mode** focuses on the need for psychic integrity (Crouch, 1994 and Fawcett, 1995), it encompasses the way in which a person sees oneself in society and includes the beliefs and feelings about oneself at a particular time (Akinsanya, 1994b). It includes the perception of both the physical and personal self. The physical self is viewed in terms of body image and body sensation, difficulties in this area are often expressed as a feeling of loss (Pearson et al., 1996). The personal self is viewed in terms of self-consistency, self-ideal and the moral-ethical-spiritual self (Fawcett, 1990), difficulties in this area can be experienced as feelings of anxiety, guilt and powerlessness (Pearson et al., 1996). The birth of the premature infant will probably have an effect on this mode as there can be an alteration in the mother’s body image after the birth, as well as a disruption of any previous organization the parents might have had, which would alter self consistency. The parents might also have a self ideal that they would like to live up to, which might be difficult to achieve with a premature infant and may cause a need for adaptation.

The **role function mode** emphasizes the need for social integrity (Fawcett, 1990, 1995); this means the knowledge of how one is in relation to others, so that one can act (The Roy Adaptation Model, n.d.). Roles are regarded as the functioning units of society (Fawcett, 1995) therefore, role function defines the sociological
role played by the individual in society and what the expected behavior of the individual is to maintain that role (Akinsanya, 1994b).

Roles are classified in three:

1. The primary role determines the majority of behaviors in a person’s life. This role is determined by age, sex and developmental stage (Andrews, 1991 as cited in Fawcett, 1995); it is relatively consistent and pre-determined (Pearson et al., 1996).

2. The secondary role, which is the most effected through the birth of a premature infant, is relatively permanent, however can be chosen, and is linked with the stages of life (Pearson et al., 1996). These roles are usually achieved positions as opposed to primary roles and need specific role performance; examples of secondary roles are parent, student or spouse (Fawcett, 1995), in this case it is the introduction of the role as a parent to a premature infant.

3. The tertiary roles are related to the other two roles, they are temporary in nature, freely chosen and relatively minor, they may include activities such as clubs or hobbies (Fawcett, 1995 and Pearson et al., 1996). This role can also be affected in this case, since having a premature infant at home could be very time consuming and thus not enough time could be available for other activities.

Each role contains instrumental and expressive components, instrumental components refer to the actual physical performance to master the role, while the expressive component refers to the feelings a person has about a particular role.
Difficulties usually arise when there is a sudden change in the secondary role for example a sudden parenthood. The inability to master a role, conflicts between roles or too many roles can all cause difficulty in adaptation (Pearson et al., 1996).

The interdependence mode also emphasizes the need for social integrity, it is the fine balance between independence and dependence on others (Fawcett, 1995 and Pearson et al., 1996). Independence is shown by the ability to achieve, make decisions and initiate actions while dependence is shown by the need for affiliation with others, for their care, support and approval (Pearson et al., 1996). This mode emphasizes behaviors underlying the development and maintenance of satisfying affectional relationships with others as well as the provision and receipt of social support (Fawcett, 1990). It involves contributive and receptive behavior that is the giving and the reception of affection respectively (Fawcett, 1995). In this mode the parents may have conflicting feelings about needing help and wanting to be able to care for their baby on their own. The lack of available social support may affect this mode.

Although these three modes have been discussed separately, they are in fact interrelated, because a certain behavior in one mode can effect another mode (Fawcett, 1995). The use of the three modes in the data collection and analysis phase of the research can be very useful in giving guidance and direction to the researcher. This model could help in identifying whether the parents’ behavioural
responses in the modes of adaptation were adaptive or ineffective. Adaptive responses promote the integrity of the adaptive system and meet the goals of survival, growth, reproduction and mastery while ineffective responses do not meet these goals (Fawcett, 1990). These behavioral responses are thought to be influenced by environmental stimuli.

The environment is considered to be all the circumstances, conditions or changes which challenge the person as an adaptive system (Pearson et al., 1996), these stimuli can be either internal or external and are categorized into three groups (Fawcett, 1995).

The focal stimuli are changes or situations which immediately affect the parents, these require immediate response to maintain an adaptive state. In this case the birth of the premature infant and the consequent discharge of the baby home would be the focal stimuli. This might lead the parents to adopt adaptive or maladaptive behaviour to cope with the situations (Akinsanya, 1994b and Tolson & McIntosh, 1996).

The contextual stimuli are all the other stimuli present in a particular situation, which contribute to the effect of the focal stimuli; they are the peripheral factors that influence the situation. These factors will affect how the parents will deal with the focal stimuli; these would include living arrangements and income (Fawcett and Tulman, 1990 and Fawcett, 1990).
The **residual stimuli** are the characteristics, beliefs, values and attitudes the parents have developed from past experience, which are affecting the current response. The parents may not be aware of these factors' influence, since they are part of their interaction with the environment, but they are not easily analyzed as part of this interaction. When the residual stimuli's effects become validated they become focal or contextual stimuli. An example of a residual stimulus would be character traits (Fawcett, 1995 and Tolson and McIntosh, 1996).

These stimuli are said to merge together to form the person's adaptation level, this refers to the person's ability to respond positively to a situation (Roy, 1991 as cited in Tolson and McIntosh, 1996). By using this model in the current research, identification of the contextual and residual stimuli can occur and thus can help in identifying why some of the parents are adapting well to their premature infant's discharge home while others are not.

Some difficulties in using the model in this research study may be complexity to categorize particular behaviors in each mode, especially in the self-concept, role function and interdependence mode, which have been noted to overlap (Fawcett, 1990, Fawcett, 1995, Hedberg Nyqvist and Sjodén, 1993 and Tolson and McIntosh, 1996). Another problem is that maladaptation is not clearly defined, thus the researcher may have difficulty in identifying it. It could also be the case that the researcher and the parents may have conflicting perceptions of positive and negative adaptation (Tolson and McIntosh, 1996). The application of this
model due to its multifaceted approach and due to its use of a wide range of concepts and principles derived from biology, psychology and sociology can also be time consuming (Akinsanya, Cox, Crouch and Fletcher, 1994).

Some authors claim that nursing models can be too restrictive, confusing or lacking in relevance to serve as guides for nursing research (Hardy, 1982, Diers, 1984, Wells, 1987 and Frissell, 1988 as cited in Fawcett and Tulman, 1990). However other authors state that the Roy adaptation model makes a significant contribution to nursing and it offers a simple and conceptually compatible framework for use in nursing research (Fawcett, 1995).

In fact, there are a number of studies based on Roy’s concepts such as studies by Bournaki, (1997), Samarel, Fawcett and Tulman, (1997), Hamner (1996) and Fawcett (1990) which all show the importance of using this model for their research (as cited in Polit and Hungler, 1999). Two research studies focusing on similar issues as the present research study and utilizing Roy’s model are those cited in Fawcett and Tulman (1990). These two studies conducted in 1988 and 1990 by the same authors focused on the maternal functioning during the postpartum period. The 1988 retrospective study was derived from the role function of the Roy adaptation model and explored the influence of focal and contextual stimuli on adaptation following child birth. The focal stimulus in this case was considered to be the type of birth and the contextual stimuli were considered to be the maternal demographic and health variables. The sample
included thirty women who had vaginal deliveries and forty women who had caesarean deliveries. Data collection occurred five years after the delivery thus the recollection period was rather long and might have influenced the data obtained. Differences were noted between caeserian and normal deliveries in the recovery of functional abilities where women delivering by caeserian section took a much longer period to recover (Fawcett and Tulman, 1990).

Similar findings were obtained in the following study in 1990, which was a prospective longitudinal study of changes in and variables associated with functional status for six months following child birth. The prospective and longitudinal nature of the study enhances the validity of the findings obtained. The study explored the associations between Roy's model adaptive modes by testing the relationship of health, individual psychosocial and family variables with functional status (Fawcett and Tulman, 1990). Findings from this study support Roy's primary, secondary and tertiary roles within the role function adaptive mode. Data from these studies also support Roy's theory of the influence of environmental stimuli on adaptation.

The review of the model showed that the person is viewed as an adaptive system constantly interacting with the environment. The premature infant's parents are interacting with stressful environmental factors, these can threaten the parents' adaptive system and will be discussed in the next section.
2.4 Parent’s experience of having a premature infant

The consequent admission of the infant to the Neonatal Intensive Care Unit is an additional stressor on the parents (Lau & Morse, 2003 refer to table 2.4.2), due to the separation from their new born infant (Charpak, Ruiz & Figueroa de Calume, 2001, Maroney, 2000). Apart from this separation from the infant and the loss of the anticipated maternal and paternal role, other concerns at this period include the infant’s survival and health crises, as well as the infant’s fragile appearance (Falleiros Mello, Melo Rocha, Silvan Scochi & Garcia Lima, 2002, Holditch-Davis, Bartlett, Blickman & Miles, 2003).

In the descriptive study by Falleiros Mello et al (2002), eleven Brazilian mothers whose low birth weight infants were hospitalized at birth were then followed up for a period of four weeks. In that period semi structured interviews were conducted to explore their experience of home care of their low birth weight infant. After hospital discharge, these mothers mainly worried about their infants' weight gain, breathing, and overall development, as well as breastfeeding, feeding, and medication preparation. However, due to the cultural difference of the Brazilian mothers results obtained could be different from those of other cultures. Nevertheless in the American descriptive correlational study by Holditch-Davis et al (2003), similar results were obtained. In the study by Holditch-Davis et al (2003), thirty mothers’ responses to having a premature infant in the NICU were examined. The study design was similar and semi
structured interviews were used for data collection, however the sample number was slightly larger as thirty mothers were involved. The follow up period was also longer and was up to six months. The interviews were audio taped and transcribed verbatim, then the transcriptions were analysed for symptoms of the three major criteria of post traumatic stress disorder, that is re-experiencing, avoidance and heightened arousal. However, in both studies the sample sizes limit the generasibility of the findings and although these findings are important, studies to replicate these findings are needed.

Another concern is the Neonatal Intensive Care Unit's strange environment (McLean et al, 2000). Parents may feel like an audience of a tragedy that concerns them profoundly, which they are unable to understand or intervene in (Charpak et al, 2001). In the study by Holditch-Davis & Miles, (2000) mentioned above mothers have reported feelings of guilt over the failure to carry the baby to term, unfulfilled expectations of their pregnancy, uncertainty about the baby's condition, sadness and helplessness Due to these factors, anxiety, depression and lack of adaptation were found to be a frequent consequence (Davis et al, 2003, Singer et al, 1999 refer to table 2.4.1). Nonetheless, personal qualities such as coping style and knowledge of infant development may help parents adapt more easily to the situation and prevent adverse outcomes (Veddovi et al, 2001 refer to table 2.4.1).
These results have been obtained from research that has been mainly concerned about the impact of the premature birth on the mothers. Less attention has been paid to the fathers’ experiences; therefore additional research including both parents is necessary so that both parents’ experiences can be explored. The present study will explore both parents’ experiences thus making an important contribution to the already present body of information.

2.5 Parents’ experiences when their premature infant is discharged from hospital

Eventually, most infants adapt to live independently from any professional support and are ready to go back to their families (Charpak et al, 2001). However, it was found that parents experience stress and anxiety even after their baby is discharged home. Most parents greet their infant’s discharge with a mixture of joy and anxiety, even though they would have been anticipating the day for weeks or even months. When the day of discharge finally arrives it can be frightening to detach from the security of the hospital environment (Antunes & Spear, 2003, Mancini & While, 2001, Wyly, 1995). This could be due to a change both in the focal stimuli as well as in the interdependence mode, as discussed in Roy’s adaptation model.

Depression may also be present on the day of discharge, especially if the infant is discharged with additional technology such as an apnea mattress, medications or oxygen (Hummel, 2003). After the baby is discharged home, the parents must
take responsibility of their premature infant, without the hospital based support and they may be concerned about their ability to care for their infants (Hummel, 2003). Taking care of a premature infant is also more time consuming, especially due to feeding difficulties and medications. Parents may also have uncertainties about the future as the child grows older and confronts new problems (Tommiska, Östberg and Fellman 2002 refer to table 2.4.2).

Preterm infants may in addition exhibit abnormal behaviour, difficulty in soothing themselves and a difficult disposition (Hoffman, 2005). The parents have to learn how to deal with their difficult premature infants as well as managing their own irritation, anger and distress (Hoffman, 2005). Taking care of premature infant at home has been associated with parenting difficulties in the first year of life (Davis, Edwards & Mohay, 2003).

Even though the premature infant is documented to sleep more total hours than a term infant, their sleep patterns are erratic and they tend to wake up more often (Trachtenbarg & Golemon, 1998). The average sleep period for a premature infant is much shorter than that of the term baby (VandenBerg, 1999). It may take up to six to eight months corrected age for the sleeping patterns to improve (Gorski, 1988 as cited in VandenBerg, 1999). The different home environment may also unsettle the infant who would have become accustomed to the brightly lit and noisy Neonatal Intensive Care Unit environment. Thus the use of soothing
music and dim lights are recommended to ease the transition (Trachtenbarg & Golemon, 1998).

In addition to these behaviours, having the premature infant home also entails the taking care of certain medical considerations. Apart from the routine medical care such as routine immunizations and vision and hearing follow ups, other medical problems have to be considered (Antunes & Spear, 2003, Bernbaum, 1994). Some of the most common medical problems parents have to face after their baby’s discharge home, are sleep apnea and a poor immune system. These make the baby more prone to infections and thus re-hospitalization (Antunes & Spear, 2003, Blackburn, 1995) Some infants who are prone to sleep apnea are discharged home on an apnea mattress. This can cause even more stress for the parents until they become used to the monitor’s presence in the home and learn how to handle the alarm (Spinner, Gibson, Wroblel & Spitzer, 1995).

In the study carried out by McLean et al (2000), twenty mothers of premature infants who needed home oxygen therapy and twenty mothers of premature infants who did not need home oxygen therapy were recruited. When questionnaires about the quality of their life were filled, mothers in both groups reported that they had less time available for family members and friends and that they had little desire to socialize. They also found it difficult and very stressful to find a reliable carer as well as to travel for outpatient visits. They also stated to have lower levels of mental health and energy. Though all the mothers were
finding it difficult to cope at home, those with the child receiving oxygen had more difficulty.

In the descriptive qualitative study conducted by Brady-Fryer (1994) the mothers' attachment to their infant and their developing relationship were explored. The experiences of their infant's hospitalization as well as their experience after their infant's discharge were explored. Six mothers were studied through the use of interviews. Multiple interviews were conducted throughout their infant’s hospitalization as well as once after discharge. A thematic analysis of the data was conducted and it was found that the preterm infant’s discharge from the Neonatal Intensive Care Unit precipitated a change in the developing mother-infant interaction. Though there was fear and mixed feelings, the positives in having the infant home far outweighed the negatives. The mothers in the study also felt that they had to get to know their infant all over again and that they had to learn how to interpret their infant’s cues and behavior. The use of multiple interviews throughout the infant’s stay as well as post discharges was very useful in collecting the mothers’ feelings throughout the study.

However, further studies are needed due to the small sample number used so as to obtain more generisable findings. The time period of the interview conducted post discharge was not set thus, there may have been a difference in the data obtained depending on the timing of the interview. The facts that premature infants were found to initiate interaction less often than term infant, and that they
provide less cues to their caregiver does not help mothers to get to know their infants easily (Davis, et al, 2003). Premature infants are also less attentive and show less positive affect, in fact, the interactions are considered to be less mutually satisfying for the premature infants' mothers (Willie, 1991). Mothers of premature infants have to work harder to initiate and maintain interaction with their babies. This can pose a risk for the development of the parent infant relationship as well as the infant's development as discussed above (Davis et al, 2003).

Numerous studies have been conducted on the Neonatal Intensive Care Unit's effect on parents. However studies exploring the effects of caring for a premature infant after hospital discharge have been fewer in number and mainly concerned the premature infants' mothers only. This emphasizes the need for further research in this area including both parents in the study. One of the most recent qualitative studies on mothers' experiences was based in Korea and was conducted by Lee et al (2005) (refer to table 2.4.1). Mothers of premature infants were found to have more concerns about infant health and they also had increased care giving burden after the baby is discharged home. This was also confirmed by other studies conducted in Korea by May and Hu (2000) and in the studies by Moon (2000, 2002), where mothers experienced more stress both immediately after birth and also while raising their babies (as cited in, Lee et al, 2005).
In Lee et al's (2005) study it was found that the mothers’ concern shifted from that of fear for the baby’s survival during the hospital stay, to concern about the physical care of their fragile infant at home. The withdrawal of the hospital support caused emotional distress and anxiety in most of the mothers (Lee et al, 2005). The main concerns were whether the infant was healthy, breathing, feeding and developing well, other concerns included bathing and medication. When infants were developing normally, mothers had a more positive attitude and were experiencing the joys of motherhood, whereas mothers whose infants had some type of problem continued to express feelings of guilt and concern about the baby’s health (Lee et al, 2005).

In this study fifty mothers were recruited which makes the sample size quiet large for a qualitative study, enhancing the rigor of this study. However, the findings are influenced by the Korean culture which is different from any other cultures thus limiting the applicability of these findings to other cultures. Since the Maltese culture is also unique, conducting a study in this context would be very useful in exploring premature infants’ parents experiences locally, thus enabling more culturally relevant information to be obtained. The results found in Lee at al’s study were also confirmed by other studies such as the one by Gennaro (1988 table 2.4.1.). In this study, forty one mothers of premature infants were found to be significantly more anxious and depressed than mothers of term infants in their first post-partal week. These feelings were also evident in the study by Kenner and Lott (1990 table 2.4.2).
<table>
<thead>
<tr>
<th>Authors</th>
<th>Aim of Research</th>
<th>Location</th>
<th>Sample</th>
<th>Design</th>
<th>Findings</th>
<th>Limitations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Singer, Salvator, Guo, Collin, Lilien &amp; Baley (1999)</td>
<td>To determine the degree and type of stress experienced over time by mothers whose infants vary in prematurity and developmental risk factors.</td>
<td>North America</td>
<td>122 high risk infant mothers, 84 low risk infant mothers, 123 term infant mothers as a control</td>
<td>Quantitative longitudinal design. Standard self report measures</td>
<td>Premature infants’ mothers had more psychological distress than term infant’s mothers. Stress did not differ after 2 years in low risk infants and after 3 in high risk ones</td>
<td>Attrition due to longitudinal design. Fathers excluded. Use of a quantitative design restricted the depth of the data acquired</td>
</tr>
<tr>
<td>Veddovi, Kenny, Gibson, Bowen &amp; Starte (2001)</td>
<td>To examine the relationship between ways of coping, knowledge of infant development and depressive symptoms for a group of mothers at the time of their premature infant’s discharge</td>
<td>Sydney, Australia</td>
<td>30 mothers of well premature infants</td>
<td>Quantitative design Self Report measures</td>
<td>Mothers who had more accurate knowledge of child development reported fewer symptoms of depression. The majority of the mothers showed signs of depression and a low coping effort.</td>
<td>Quantitative design thus data obtained was not in-depth. Response rate was 67% there were a relevant number of respondents were lost. Fathers excluded.</td>
</tr>
<tr>
<td>Lee, Norr &amp; Oh (2005)</td>
<td>To explore the emotional adjustment and concerns of mothers of premature infants from hospitalization through to six weeks after discharge</td>
<td>Teague, Korea</td>
<td>50 mothers of premature infants.</td>
<td>Qualitative Design 3 face to face interviews, 2 telephone interviews using 4 open ended questions.</td>
<td>The birth of a premature infant caused intense emotional distress and concern, after discharge the mothers continued to express distress and concern especially when the infant had problems. Main concern was the infant’s health.</td>
<td>Findings are influenced by the Korean culture, thus reducing applicability of results</td>
</tr>
<tr>
<td>Gennaro (1988)</td>
<td>To examine differences in anxiety and depression in mothers of term and preterm infants in the first week postpartum and over the next 6 weeks</td>
<td>USA</td>
<td>41 preterm infants’ mothers and 41 term infants’ mothers having same parity and background were compared.</td>
<td>Quantitative design self report tools</td>
<td>Mothers of preterm infants were significantly more anxious and depressed than mothers of term infants in the first week but difference did not persist over time. Level of infants’ illness did not affect anxiety levels.</td>
<td>Fathers excluded. Findings not in-depth. Study rather old.</td>
</tr>
</tbody>
</table>

Research studies concerning parental experience after the discharge of their premature infants home. Table no 2.4.1
This also showed that mothers experienced feelings of concern and helplessness in the first week. Anxiety and stress levels were found to start decreasing after the first week of being discharged home (Gennaro, 1988). In the study by Tommiska et al (2002), parents seemed to recover well from their initial stressful experience by the time their infant was two years of age (refer to table 2.4.2). A limitation to these studies is the fact that background data was not provided and this could influence the parents’ experiences. Thus in my study some background data has been obtained as to analyse its influence on the parents’ experiences.

Lau and Morse (2003 table 2.4.2), found that even though parents of premature infants were highly stressed within the few days of the birth of their premature infant, stress levels decreased drastically sixteen weeks after the infant was discharged home. In this study both parents experiences were explored over a period from admission till sixteen weeks post discharge. This makes the findings of this study an important source of information to explore paternal feelings as well as maternal ones. The experience of mothers and fathers were also compared in the longitudinal study conducted by Tommiska et al (2002 refer to table 2.4.2). Stress levels were found to be similar in both parents and the decrease in stress levels was also found to be comparable.

The reduction in stress levels by the both mothers and fathers could be due to the fact that the parents have overcome their initial shock and were adjusting to caring for their premature infant at home (Lau & Morse, 2003). Stress levels may
also decrease because parents of premature infants spend a longer time at hospital and thus are more trained in caring for their babies. Parents end up being more competent care givers than the term infants’ parents (Lau & Morse, 2003). The decrease in anxiety was also associated to improvement in the baby’s condition and discontinuation of equipment (Zanardo and Freato 2001).

Zanardo and Freato (2001), attempted to define the evolution of anxiety levels in a population of parents of low-birth-weight premature infants with bronchopulmonary dysplasia enrolled in a prospective home oxygen therapy program. A questionnaire was given to ten parents of premature infants immediately pre-discharge. Subsequently, the parents were assessed twice, initially after a week from the discharge of their infants and then at the end of the oxygen therapy phase. The results indicate that these parents portray an increased state anxiety level upon hospital discharge of their oxygen-dependent premature infants, which decreases as the child’s condition improves. The sample has been rather small thus results may not be applicable to other parents

Different results were obtained in the study conducted by Holditch-Davis and Miles (1995), which explored whether mothers' recollections surrounding the birth and hospitalization of a preterm infant affected their perceptions and their parenting. Twenty seven primary caregivers of thirty prematurely born children completed three questionnaires on their perceptions of their children and were interviewed about parenting experiences. Mothers of premature infants were
found to continue to have feelings of anxiety and depression for more than six months after hospital discharge. They also were reported to have distressing memories of the birth and neonatal intensive care experience for up to three years. This conflicting result was also present in the findings of Holditch-Davis et al (2003) were mothers experienced symptoms of post traumatic stress disorder at three and six months after discharge. In both these studies sample number was small thus limiting generalizability of the findings.

Further limitation with these studies results could be due to the longitudinal nature of the studies and thus to the risk of attrition. However the longitudinal nature of the study also enhances the richness of the data collected. Another limitation could be that the premature infants in the sample of Lau and Morse, 2003 (refer to table 2.4.2) did not have life threatening conditions upon discharge thus the severity of their condition was minimal. Whereas in the study by Holditch-Davis et al (2003) the premature infants had life threatening conditions.

On the other hand, there are also contradictory results regarding the effect of having a high risk infant compared to having a low risk infant. This factor was not found to influence parental stress levels in the study by Padden & Glenn, (1997) where the maternal experiences of preterm birth and neonatal intensive care were explored through interviews. Thirty six mothers of infants born between 27 and 34 weeks gestation were interviewed to explore their experiences. Interviews were conducted between four and nine days following birth, when infants were no
longer considered to be critically ill. The emotional reactions of parents with critical premature infants was found to be similar to those with a less critical condition.

In fact, in the study by Veddovi et al (2001 refer to table 2.4.1), the majority of mothers in the study reported symptoms of postnatal depression and coping effort below the community norm. In this study the mothers of well premature babies were recruited thus showing that even though the premature infants did not suffer from potentially life threatening conditions the mothers still were suffering from stress and anxiety.

On the other hand, the findings achieved by Singer et al (1999, table 2.4.1), showed that at two years of age mothers of low risk infants did not suffer from undue stress when compared to mothers of term infants, whereas mothers of high risk infants continued to report feelings of psychological distress. No difference was noted in distress levels at three years of age in both groups. The fact that low risk mothers did not show feelings of distress at two years of age surprised even the researchers themselves. They attributed this difference to feelings of relief on the mothers’ part that their child was developing normally (Singer et al, 1999). These contradictory findings emphasize the need for further studies so as to explore these aspects in more detail.
<table>
<thead>
<tr>
<th>Authors</th>
<th>Aim of Research</th>
<th>Location</th>
<th>Sample</th>
<th>Design</th>
<th>Findings</th>
<th>Limitations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kenner &amp; Lott (1990)</td>
<td>To explore the transition parents undergo after their infant's discharge from a Neonatal Intensive Care Unit.</td>
<td>United Kingdom</td>
<td>10 parents</td>
<td>Qualitative design. Interviews</td>
<td>Parents experienced anxiety before and after discharge of their preterm infant, especially in the first week post discharge. Parents reported a large gap between their needs and concerns and the health care providers' perceptions of their needs and concerns.</td>
<td>Small sample size thus limiting the generalizability of the findings.  Since one interview was conducted after discharge there may have been loss of information which may have been obtained through further interviews.</td>
</tr>
<tr>
<td>Tommiska, Östberg &amp; Fellman (2002)</td>
<td>To compare the parental stress in the families of 2 year old extremely low birth weight infants with that in control families and to compare the stress of mothers with that of fathers.</td>
<td>Helsinki, Finland</td>
<td>Families of 74 extremely low birth weight infants and families of 75 full term infants as a control group.</td>
<td>Quantitative design Neurological examination, developmental assessment of the infants at 2 years of age Questionnaires Given to the parents.</td>
<td>Stress levels were not found to be different in the mothers and fathers. After two years most parents had coped well with the situation and recovered as they did not have more stress than the control group.</td>
<td>Fathers' response rate was low therefore the results comparing the mothers and fathers reaction may not be very accurate. Use of questionnaire thus limited response.</td>
</tr>
<tr>
<td>Lau &amp; Morse (2003)</td>
<td>To determine the stress experiences of parents whose premature infants were admitted to a special care nursery.</td>
<td>Melbourne, Australia.</td>
<td>60 mothers and 60 fathers of premature infants. Control group same number of parents of term infants.</td>
<td>A controlled prospective longitudinal design Data collected from the parents separately on 5 times up to 16 wks post discharge. Questionnaires.</td>
<td>Parents of premature infants were stressed within the first few days of the birth of the infant but stress levels decreased by 16 weeks after the infant’s discharge home. Parents of premature infants were more stressed than parents in the control group</td>
<td>Attrition due to longitudinal nature of the study. Use of questionnaires limited the in depth nature of the data collected.</td>
</tr>
</tbody>
</table>

Research studies concerning parental experience after the discharge of their premature infants home. Table no 2.4.2
Feelings of anxiety and stress were found to be further enhanced at times of stress in the child’s life, for instance when the child is ill or if the child has behavioural problems and developmental difficulties. It is believed that such events revive the feelings of helplessness, frustration and fears for the child’s life similar to those felt when the infant was still hospitalized in the Neonatal Intensive Care Unit. This has been described as chronic sorrow (Hummel, 2003). Even if the infant is developing normally and has no problems parents may still experience grief (Hummel, 2003). Thus if parents are reassured these feelings are common they may at least be comforted that they are not behaving abnormally.

One way to manage all these negative feelings is through the utilization of effective coping strategies. Since the hospitalization of an infant brings the parents in close contact with nursing staff and other health care professionals, it would be ideal if coping strategies are taught and reinforced by these staff (Davis et al, 2003). This can only help in promoting family stability and the parent-infant relationship, thus indirectly also helping in the infant development (Davis et al, 2003). The development of adequate coping skills should be part of the discharge plan, which is important to adequately prepare the family to provide good care for the premature infant in the home setting (American Academy of Paediatrics, 1998)
2.6 Discharge Planning

Discharge planning in the Neonatal Intensive Care Unit should be a multidisciplinary effort that should begin at the infant's birth and admission to the unit (Drake, 1995, Trachtenbarg & Golemon, 1998). Most hospitals have established discharge rules and guidelines (Charpak et al, 2001, Edwards, 1994). These are mainly based on biological end points, such as the achievement of certain milestones of maturity as well as a fixed age and/or weight (Charpak et al, 2001). Sometimes, in preparation for discharge the premature infant will be moved down to an intermediate care nursery (Antune & Spear, 2003, Edwards, 1994). There is also often the opportunity that the parents do a period of rooming-in with the infant where the parents are allowed a brief stay in a hospital room with the baby. This is done so that they gain some hands on experience in taking care of their baby with professional support close at hand (Antune & Spear, 2003).

An important aspect of discharge planning which is being increasingly recognized, even in guidelines is the importance of educating the parents as well as the availability of appropriate support services (American Academy of Paediatrics, 1998). A premature infant’s discharge home is a challenging situation for both the nurses and the parents (Drake, 1995). To make this transition easier Vecchi, Vasquez, Radin and Johnson (1996) suggest keeping the parents
informed about the expected sequence and time frame for their infant’s discharge so that they will not be taken by surprise.

A significant aspects found in the literature, which must be included in the discharge plan was parental education. The anxiety among parents who are awaiting their infant’s discharge may stem from a perceived lack of knowledge about their infant care, as well as lack of experience of caring for their infant (Kenner & Lott, 1990). Therefore, educating the parents about their child’s care is an essential component of the discharge plan. They need to be carefully prepared for this transition with appropriate advice and support, so that they will be as confident as possible in their ability to care for their infant (Mancini & While, 2001). In the study by Mancini and While (2001), parent’s views on discharge planning of their baby were explored. The study utilized both quantitative and qualitative approaches, with the use of semi structured interviews which consisted of both structured and open questions. A convenience sample of sixteen parents of premature infants was used and the interviews were conducted one day prior to discharge, as well as six weeks after discharge. Results showed that neonatal nurses were seen as the most important sources of support and information, most parents were satisfied by the information received, however, a lack of information on infant development and recognition of ill health was noted. The main concern identified was feeding issues. The results obtained through the study are very useful, however, replication is required since the study sample was small and generalization is not possible.
Positive effects of education prior to discharge were shown in the study by Meyer, Garcia, Lester, Boukydis, McDonough & Oh (1994), who tried to determine the efficacy of an individualized, family-based intervention with preterm infants and their families. A random sample of thirty four preterm infants and their families participated in this study, which involved the administration of individualized, family-based intervention during the hospitalization and transition to home. These interventions addressed problems identified by parents such as, infant behavior and characteristics, family organization and functioning, caregiving environment, and home discharge. Standardized questionnaires were administered on admission and discharge to the mothers, and pre-discharge bottle-feeding interactions were videotaped. Results showed that mothers were less depressed, feeding difficulties were less frequent and the parent infant interaction was more positive when they were given a proper education throughout the infant’s stay in the Neonatal Intensive Care Unit (Meyer et al, 1994). Although replication of such studies is very important duplication is difficult since the intervention with the parents are so individualized.

Teaching parents how to care for their infant in the intensive care unit environment can be a challenge. Parents often need a great deal of repetition and interpretation of explanations due to the stressful period they are in (Drake, 1995, Flanagan, Slattery, Chase, Meade & Cronewett, 1996). From the quantitative pilot study conducted by Flanagan et al (1996), it was found that mothers emphasized the importance of communication with health care
providers for a reduction in stress levels during the transfer of their infants to a nursery. The pilot study was done to test an instrument which measured mothers' perceptions of the quality of the back-transfer experience from a Neonatal Intensive Care Unit to a community hospital and forty one mothers participated in it. However, further research is needed to support the findings, since this was only a pilot study and response rate was only 55%, which is quiet low. To ensure that the parents are well informed about their child’s care and development, reinforcement of their education should be done after the infant’s discharge (Trachtenbarg & Golemon, 1998).

Parents are considered as adult learners, thus self identified needs are considered to produce higher levels of motivation to learn then externally identified needs (Harrison, 1990). If the needs are identified by the parents themselves they would be more appropriate and useful for them (Drake, 1995). Therefore, every discharge teaching plan should be individualized to meet the parents’ and the infant’s needs (Costello et al, 1996). Through the exploration of parents experiences upon the discharge home of their premature infants such needs may be identified.

Understanding the principles of adult learning alone is not enough to provide adequate education, the nurses providing discharge teaching must take in consideration the anxiety parents are experiencing, which can inhibit learning (Drake, 1995). It is better if information is given gradually to the parents rather
than in one session as it was found that parents respond better to such information. It is also important that the information given is pertinent to their infant's condition and to their needs (Costello et al, 1996).

Educating the parents is important, especially regarding the child's development, since this is one of the most worrisome factors for parents of premature infants (Hussey-Gardner et al, 1998). Veddovi et al (2001 table 2.4.1) found that when mothers have a greater knowledge of child development, they reported fewer signs of depression at their baby's discharge than those mothers with less knowledge. Thus, interventions that provide information about important aspects of child development may be protective, or at least may alleviate symptoms of depression and therefore, contribute positively to parenting and child development (Veddovi et al, 2001).

Other important aspects include the parents' involvement in their infant's care, especially in feeding skills. As already mentioned, feeding is a crucial activity for a premature infant because this interaction can have a major impact on the infant's growth and development. Parents, feel that feeding their premature infant as an emotionally loaded experience as well as technically demanding. Thus, it is essential that good feeding skills are taught to the parents previous to their infant's discharge home (Pridham et al, 1998). Parents should also be helped to develop new care giving competencies, or revise and extend old ones. This is important since the level of development of these care giving competencies has
implications for the child’s health, growth, development and relations (Rutter, 1995 as cited in Pridham et al, 1998). Such development could be promoted through participation of parents in their infants care as early as possible. This has been said to have a positive effect on their confidence to handle the baby and their readiness to assume full responsibility of their infant’s care at home (American Academy of Paediatrics, 1998). In this way the parents take home an infant they know rather than one they consider a stranger and have to get to know (VandenBerg, 1999).

Other educational needs identified by the parents themselves, include plans for special needs such as oxygen use and apnea monitoring and teaching the parents special skills such as cardiopulmonary resuscitation (Falleiros Mello et al, 2002, Langley et al, 1999, Trachtenbarg & Golemon, 1998). Information concerning the recognition of signs and symptoms of ill health was also considered by parents to be an important issue (Drake, 1995, Mancini & While, 2001).

Additional aspects of the discharge plan include the identification of support available for the family. This is very important since in the study by Morawski Mew et al, (2003), it was found that social support was related to a decrease in depressive symptoms when factors related to depressive symptoms in preterm infant’s mothers were explored. Since the study was correlational, patterns of the changes in maternal depression over time could not be identified. Sample size was also small thus limiting generalizability of the data. Lack of social support was
related to higher levels of distress in the study conducted by VandenBerg (1999). Further studies are needed to identify the effect of social support on the coping skills of these parents, through the exploration of their experiences the effects of social support can be identified.

The last aspect of the discharge plan involves the implementation of primary care where, administration of immunizations, assessment of vision and hearing and follow up appointments with a neonatologist are taken care of (American Academy of Paediatrics, 1998). These follow up clinics are essential to facilitate early detection of any developmental problems (Hussey-Gardner et al, 1998).

2.7 Follow up Care

After the infant is discharged from the Neonatal Intensive Care Unit, nurses must remember that these parents are still suffering from anxiety, especially if problems arise, but even if the baby is doing well. Continuing to support these parents and validate their parenting skills is critical (Hummel, 2003). In fact in the quantitative study by Affleck, Tennen, Rowe, Rocher and Walker (1989), positive effects were noted for the provision of formal support after discharge. Ninety four mothers were randomly assigned to a control group or to a group who received a formal support program designed to aid their adaptation to the transition from hospital to home care. This enhanced the reliability and validity of the results obtained. The mothers in the formal support group had a better sense of
competence and felt more in control when their infants had problems. However, in mothers whose infants were healthy and well behaved these positive effects were not evident (Affleck et al, 1989).

The knowledge that support and advice are available whenever needed was found to facilitate the transition from hospital to home and to decreases the parental stress levels (Emmanuel & Knight, 1999). This advice is also important to reinforce what has already been taught in hospital, thus building parental confidence and ensuring that the information has been understood (Emmanuel & Knight, 1999). The use of home visits by skilled nurses has been suggested to be extremely successful, as they are believed to be useful in decreasing stress and in increasing parents coping abilities (Edwards, 1994). Home visits are thought to be very supportive for parents, especially if the nurse doing the home visit was one of the nurses who worked in the Neonatal Intensive Care Unit (Barton and Lawlor-Klein, 1994). This was also emphasized by Wilson and McMurray (2001), who also accentuated the importance of assessing the parents well being. Then, if signs of depression are visible, the nurse has to refer to mental health professionals as well as just giving support (Beck, 2003). If home visits are difficult to provide, a telephone call was also found to be useful in providing support (Lee at al, 2005).
2.8 Conclusion

Since the rate of prematurity survivors has increased dramatically (Hussey-Gardner et al., 1998), the premature infant parents who were shown to experience stress and anxiety, as well as depression have also increased in numbers. Hence, more importance should be given to ensure that additional care is provided to these parents, so as to ease their stressful experience as much as possible. Even though the transition for a premature infant from hospital to home is a long anticipated event for the parents and they are very excited for their infants' homecoming (Brady-Fryer, 1994, Wyly, 1995), this transition has been also shown to evoke fears and doubts about their ability to care for their baby as well as concerns about their infants health and possible future problems (Lee et al., 2005, Tobey and Schraeder, 1990).

Preparation for discharge from the Neonatal Intensive Care Unit to home through education and practical experience with their infant, has been shown to provide a smoother transition for families and to make discharge less of a crisis (Lee et al., 2005, Wyly, 1995). A follow up home visit or at least a telephone call has also been shown to be important in decreasing parental stress in adapting to this situation, since parents cannot retain all the information they have been presented with before discharge (Lee et al., 2005).
Since the Maltese culture is unique in its nature it is important that a study exploring parental experience after their premature infant is discharged from the Neonatal Intensive Care Unit is conducted locally. Results from previous studies though helpful in giving a perception on this issue cannot give the insight on the Maltese parents’ experience since they were conducted in different countries such as America, United Kingdom, Korea, Australia and Finland. Also the studies conducted in this area have mainly concerned maternal experiences. In this study both parent experiences will be explored thus helping to identify fathers’ experiences as well.
CHAPTER 3: METHODOLOGY

3.1 Aim of the Study

The aim of this study is to explore the experiences of parents following the discharge of their premature infant home.

3.2 Research Question

"What is the lived experience of parents, following the discharge of their premature infants' home?"

3.3 Operational Definitions

Premature infant: An infant born before the 37th week of pregnancy. (www.umassmemorial.org/ummhc/hospitals/med_center/services/NICU/glossary.cfm)

Experience: Experience as a general concept, comprises knowledge of or skill in or observation of some thing or some event gained through involvement in or exposure to that thing or event. The history of the word experience aligns it closely with the concept of experiment (http://en.wikipedia.org/wiki/Experience, 2005).
Parent: One who begets, gives birth to, or nurtures and raises a child; a father or mother. (The American Heritage Dictionary of the English Language, 2000).

3.4 Research Approach

Debates about the use of qualitative researcher and the positivist approach in nursing research, have been arising since the 1970's. Since nursing is concerned with the real world of practice, the research methods used had to be able to generate meaning from the people involved in nursing, that is, the nurses and patients (Taylor, 1993). Nursing was beginning to be considered as a human science, rather than a natural science such as biology and chemistry (Munhall, 1988, Fjelland & Gjengedal, 1994). Deciding on the type of research method to be used depends on the questions being asked (Leonard, 1994). Thus in this case the decision to choose a qualitative research approach was taken because I was interested in exploring the parents' experiences when their premature infant was discharged home. Some questions, such as, procedural techniques or healing regimes can be explored using quantitative methods (Taylor, 1993), however to use these methods in exploring the human life experiences is being questioned (Van der Zalm & Bergum, 2000). The use of qualitative research is important in nursing because the expression and description of human experience is considered indispensable in the basis of nursing practice (Todres & Wheeler, 2001). Also the interpersonal environment in which nursing occur, provides a rich supply of
verbal and behavioral interactions from which meaning can be interpreted and

I chose phenomenology for the present study because it is considered as a
research method that could provide understanding in the parents’ reality and
experience and one that views a person holistically (Oiler 1982). It is a type of
qualitative research method that offers a new way to interpret the nature of
consciousness and an individual’s involvement in the world (Beck, 1994a). It
seeks to understand the perspectives of those being studied and is interested in
people’s lived, intersubjective experiences of their world (Taylor, 1993), so in this
case it was considered to be the best methodology to use to explore parents’
experiences.

3.5 The philosophy of Phenomenology

Husserl is regarded as the founder of modern phenomenology, his fundamental
concern was an epistemological one, that is, to provide a foundation for
knowledge (Todres & Wheeler, 2001). In Husserl’s transcendental
phenomenology, the goal is to describe human experience as it is lived,
phenomena are described as they are consciously experienced (Beck, 1994a). He
emphasis the importance of describing the phenomena free from bias,
preconception or presupposition (Jasper, 1994). This is done through reduction
and bracketing, which involves the researcher becoming aware of one’s
consciousness, concentration on the phenomenon, becoming absorbed in it and seeing it as if for the first time (Rose, Beeby & Parker, 1994).

However, I chose an interpretive approach for this study rather than Husserl’s transcendental philosophy. The main reason was because I agreed with Husserl’s student, Martin Heidegger’s argument that it was not possible to bracket one’s being in the world (Walters, 1995, Wimpenny & Gass, 2000, Lowes & Prowse, 2001). He offered an alternative view regarding bracketing, he believed that as human beings, meaning is co-developed (Byrne, 2001), and also declared that people are in the world, rather than subjects in a world of objects. World in phenomenology has a different meaning, it is the meaningful set of relationship, practices and language that one has by being born in a culture (Leonard, 1994).

Heidegger’s phenomenology considers people interacting with their world and focuses on ontological issues and what it is to be a person (Walters, 1995, Leonard, 1994). It emphasizes understanding rather than description and this is the main aim of the current study, that is, an attempt to understand the parents’ experiences after their infants are discharged home (Burke Daucker, 1999). Heidegger (1972), argued that nothing can be encountered independent to a person’s background understanding and this causes interpretation based on this background, at that particular time, that is, in its historicality (as cited in Koch, 1996, Leonard, 1994) and in the social context of the experience (Burke Daucker,
1999). The presuppositions the researcher brings into the research should be examined and explained, rather than suspended (Burke Daucker, 1999).

My presuppositions concerning the study include the fact that I work as a staff nurse in the Special Care Baby Unit, thus I have participated in the discharge of preterm infant. To prevent bias in the study results as much as possible, I did not take care of the infants in my sample and did not participate in their discharge plan. I believed that the discharge planning offered at SCBU was lacking, this was what inspired me to start the study in the first place. I thought that the parents once discharged home, would feel lost and would have needed additional professional help at home to cope with their premature infant. The fact that I do not have children of my own also makes my idea about babies different from that of the parents participating in the study. These presuppositions were written in a journal and kept in mind throughout the study so as not to bias my interpretations during the data analysis.

3.6 Research Design

I chose an interpretive phenomenology methodology because it provided insight and understanding of the parents’ reality and experience and it also offered a holistic view of the person (Oiler, 1982). It provided an insight to parents’ ways of being in the world rather than providing a theory for generalization (Dreyfus, 1991 as cited in Crist & Tanner, 2003). In accordance with this design the
participants and myself were viewed as sharing common practices, interpretations and everyday understandings due to our common culture and language (Leonard, 1994).

Once the research question was designed, a literature review was undertaken before the generation and interpretation of the data. Some qualitative researchers object to this, as they affirm that a literature review may lead to bias (Lowes & Prowse, 2001). However, since in Heideggerian phenomenology, a researcher’s preconceptions are part of the research process, the idea that a literature search creates bias is irrelevant (Lowes & Prowse, 2001), as long as its influence is noted (Koch, 1995). Thus I decided that the benefits of conducting a literature review outweighed the risks of biases since, through the conduction of a literature review the involvement of people in unnecessary research was prevented. This would be unethical as well as a waste of resources (Lowes & Prowse, 2001). Through the literature review, sample size and research questions were also generated.

3.7 Target Population and Sampling Techniques

The sample size is considered sufficient when interpretations are visible and clear and no new findings and meanings are being discovered (Crist & Tanner, 2003). An interview with six participants was found to be sufficient for data saturation. The target population were the premature infant’s parents as they would be the most capable to describe their experience and feelings.
Six parents of premature infants who were between 30 and 36 weeks gestation on admission, were recruited. The parents were recruited in the Neonatal Intensive Care Unit prior to their infant’s discharge. To obtain a sample adequate for the research study inclusion criteria were established. In this way a sample that effectively revealed what the parents’ experience of their premature infant meant to that particular group was obtained (Creswell, 1998). Criterion sampling is useful in phenomenology so that all individuals studied have experienced the phenomenon under study (Creswell, 1998). Random sampling was not considered to be the best method of selecting people who would have made good informants for this qualitative study (Polit & Hungler, 1999), thus a criterion sample was chosen.

The sample was composed of parents of premature infants who met the following criteria:

- The premature infants did not need ventilatory support after they were born, since this was found to cause higher parental stress (Haines, Perger & Nagy, 1995) and would thus affect the parents’ experiences. The baby would also have had a longer stay at SCBU and this would influence the amount of information they would be given and their level of preparation would also be different.

- Single infant deliveries were chosen as multiple deliveries have been shown to cause more stress both during the Neonatal Intensive Care Unit stay and post
discharge, due to having two or more babies to take care of (Shields & Pinelli, 1997).

· The infants’ gestation at birth was between 30 and 36 weeks since premature infants who are born less than 30 weeks gestation are ventilated upon delivery according to the local Neonatal Intensive Care Unit protocol.

3.8 Research Instrument

The main data collection method in this type of research was a semi structured interview, as it was considered to provide an opportunity to explore, illuminate and gently probe participants’ descriptions (Wimpenny & Gass, 2000). Interviews are adequate to study sensitive issues and for increasing the response rate (Barriball & While, 1994, Parahoo, 1997). The main limitation of interviews is that there is the risk of response bias, where some respondents may distort their responses to provide more favorable images of themselves (Polit & Hungler, 1999). This problem is difficult to prevent, however, the researcher tried to prevent this as much as possible through the use of subtle and indirect questions (Polit and Hungler, 1999). Other limitations include the fact that they are costly and more time consuming. Another issue is that anonymity was not possible since the participants had to meet the researcher face to face.
Some degree of structure was used in the interview, so that as Britten (1997) points out, the data collected was relevant to the research question (as cited in Lowes & Prowse 2001). In fact, a semi-structured open-ended interview schedule was used (Appendix 2 and 4), this was created by myself on the information obtained through the literature review. Even though the schedule was set before the study began, it evolved slightly during interviews and observations as meanings, practices, and concerns, emerged from different perspectives (Crist & Tanner, 2003). The interview schedule was done both in Maltese and in English, however, all the interviews were conducted in Maltese as it was the preferred language of the participants.

The use of a semi-structured interview schedule made the best use of resources such as participant and interviewer time. It also gave the participants the opportunity to describe their experience in their own words, thus allowing the researcher to gain more insight into the parents' experiences, to gather more meaningful data and to keep the participants on track (Barriball & While, 1994). Transcription of the interviews was done if possible on the same day the interview had taken place so that subtleties of interaction and unclear parts were easily remembered (Cormack, 1999). This was especially important in the parts where both parents spoke together as these recordings were difficult to understand.

An interview was conducted with both parents at two weeks post discharge. The time period was chosen in this way because the first week at home after discharge
has been found to be a period of heightened anxiety, related to infant care and maternal fatigue (McKin, 1993 as cited in Lee, Norr and Oh, 2004). Thus, it was not considered to be ethical to conduct the interview in the first week at home as they would still be settling down. The second week was considered to be better so that the experience of the transfer from hospital to home would still be fresh and easily remembered. A second meeting was set up two weeks after the first interview, to obtain any missing data, as well as to clarify ambiguous parts. A third meeting was also held two weeks after the second meeting, to discuss the researcher’s interpretation of the interview data. This was useful for verification purposes. These two meetings were important to confirm the interpretations and to clarify any ambiguous parts with the participants themselves, as well as to ask about any missing data (Crist and Tanner, 2003). The two week gaps were chosen so that the participants would not forget the information given in the previous interview and it was not done before so as not to cause too much inconvenience to the parents in a short period of time.

The use of multiple meetings with the same participants allowed the researcher to revisit issues and discuss new areas that would have arisen from the previous interviews, as well as making the parents more relaxed, open and truthful with the researcher (Whitehead, 2004, Conroy, 2003). In this way deeper insights (Mishler, 1986 as cited in Crist & Tanner, 2003) and with less response bias were discovered (Polit & Hungler, 1999). Seidman (1991) recommends that at least three interviews are carried out with each participant (as cited in Crist & Tanner,
Jasper (1994), emphasize the importance of skills such as the use of reflection, clarification, requests for examples and descriptions and good listening techniques, for a good interview to be conducted. These were attempted to the best of my capability, I already had some experience in interviewing people from a previous study in which interviews were used as a method of data collection.

Each interview was tape recorded so that no data was lost, according to Whitehead(2004), the quality of data produced overweighs the distraction produced by the recorder. It also provides a detailed insight into the performance of both the interviewer and interviewee(Barriball & While, 1994). Throughout the interviews, field notes were taken such as expressions and gestures as these would not be audible in the recording (Crist & Tanner, 2003).

The interviews were conducted at the participants’ convenience and in the home environment, to encourage as much participation as possible, especially due to the fact that all the participants had a small baby to take care of (Whitehead, 2004). The participants were all asked the same questions, but there was flexibility in the phrasing and order of the questions (Parahoo, 1997) In this way the validity of the interview was enhanced since the participants could be helped to understand the questions. The interviewer was also able to ask for clarification and probe for further responses if necessary. Care was taken that neutral probes were used so as not to influence the content of the participants’ response (Polit and Hungler, 1999).
3.9 Pilot study and modifications

A pilot study, which is a small scale version, or trial run in preparation for the major study (Polit & Hungler, 1999), was done to pretest the interview schedule. This was done to ensure that the questions were easy to follow and understand and that they were appropriate to obtain the required data. The pilot work was also useful in determining the timing of the interview and data transcription (Polit & Hungler, 1999). The recording equipment was also tested to ensure that the recording was clear.

The pilot study was conducted with one set of parents, since according to Parahoo (1997) 20 to 30% of the whole population is enough for a pilot study in qualitative research. The interviews were conducted at their own home. This helped in their availability and in the fact that they were more relaxed. The length of each interview was about forty minutes, while the transcription of each interview was established to be two to three hours. The interview schedule seemed to be appropriate as the information obtained was relevant to the research question being asked. No changes were done to the interview schedule after the pilot study as the information obtained from the interviews answered the questions being asked appropriately. Due to this the results from the pilot study were included with the main data since the data obtained in the pilot study was important for the study.
3.10 Evaluating the research design

When evaluating this interpretive account, it was kept in mind, that there can never be an interpretation free, objective account and that there is no technical procedure for validating a particular account (Leonard, 1994). Issues of reliability, validity and generalizability were not used in this phenomenological study as these were considered to be more suitable for the positivist approach (Keddy in Beck, 1994b, Parahoo, 1997). A more appropriate method was considered to be Lincoln and Guba’s (1985) concept of trustworthiness, in fact this was used to evaluate this research study (as cited in Tobin & Begley, 2004). This involves the criteria of credibility, transferability, dependability and confirmability.

Credibility which refers to the reality of the results, that is that they show what the respondents really said, was ensured by identifying and documenting preconceptions and possible effects of these preconceptions in a journal. This was done to keep track of the researcher’s understandings, misunderstandings and biases (Donalek, 2004, Conroy, 2003, Koch, 1996). This was essential to demonstrate that these preconceptions and biases did not determine the results (Lowes & Prowse, 2001). This was also ensured by asking the participants in the second and third meeting to confirm the interpretations of the researcher and also make further contributions.
Transferability, which is comparable to external validity refers to the generalizability of the results. However, in this case the generalization refers to case to case transfer only (Tobin & Begley, 2004). The data collected was similar in all the cases, showing that data could be transferred to similar cases.

Dependability which is comparable to reliability, was achieved through a clear documentation of the research process, to show that the research process was logical and easily traced (Tobin & Begley, 2004). An audit trail could be done to demonstrate dependability, where other people can analyse the researcher’s documentation of data, methods, decisions and end products (Tobin & Begley, 2004). In this case the transcripts were given to a colleague so that confirmation and double checking of the analysis and extraction of themes was done.

Confirmability is comparable with objectivity and neutrality, this was ensured by showing that the data and interpretations were not figments of the researcher’s imagination, but were derived from the data (Tobin & Begley, 2004). This was shown by using verbatim extracts to show from where the themes were extracted.

Another important aspect indicating the rigour of a qualitative study was the statement of the philosophical underpinnings of the study, that is, an interpretive phenomenological approach and confirmation that the methodology used was the same as the philosophy chosen. Therefore, to ensure quality, an affiliation to
Heidegger’s philosophy and methodology was maintained (Lowes & Prowse, 2001, Rose, Beeby & Parker, 1995).

Face validity of the interview guide was obtained from the dissertation panel of the Institute of Health Care and the reliability of the interview guide was enhanced by pre testing the interview guide in the pilot study.

3.11 Limitations of the research design

The problem with these methods is that, conducting a phenomenological research was time consuming due to the use of multiple interviews, transcriptions and in depth analysis. It was also expensive and depending on the topic can be emotionally involving, since the data gathered is very in-depth (Whitehead 2004). However, this was not the case in this research study since most of the parents expressed positive feelings. Another drawback in this case was that the researcher was also the healthcare provider and the two roles could be viewed as conflicting (Lowes & Prowse, 2001).

Since prior to the premature infants discharge home, the researcher used to work at SCBU, some of the parents still saw the researcher as the health care provider, in fact many times advice regarding their infant’s care was sought. The participants were informed that when conducting interviews the role was that of a researcher rather than a health care provider and that if any advice was needed it
would be dealt with after the interview was over. The fact that the participants knew the researcher from before hand helped in the building of trust and thus more truthful data could be generated.

3.12 Ethical Considerations:

Permission to conduct the study was sought and obtained from the M.Sc. Health Science Nursing and Midwifery Board of Studies, Institute of Health Care Board, University of Malta Ethics Board, the Health Care Ethical Committee, Chairman of Paediatrics (Appendix no.6) and the premature infants’ parents themselves. The main ethical considerations for this study are the issues of anonymity, confidentiality, autonomy, informed consent and the protection of the participants from discomfort (Burns & Grove, 1995, Polit & Hungler, 1999).

Since face to face interviews were used in this study, total anonymity was not possible, therefore appropriate confidentiality procedures were used and confidentiality was ensured in the publication through the use of pseudo names. The participants were assured that the information provided would not be publicly reported in a way that they would be identified and that the information given would only be used for the purpose of the study (Polit & Hungler, 1999). Also a non-sequential coding system was used to label the interviews instead of the participants’ names.
Signed informed consent was obtained. Prospective participants were asked to participate in the study and information regarding the study was given both in persona and in writing (Appendix 3 and 5). Oral presentations provided opportunities for greater elaboration and for participant questioning so that the participants could understand the information given better (Polit & Hungler, 1999). Only one set of parents refused to take part in the study the reason being that the father was too busy working and did not have time to take part in the interviews.

Sensitivity on the part of the researcher was enforced and the participants were also informed that they were free to stop the interview whenever they felt uncomfortable. They were also informed that they were also free to refuse to answer questions that they felt were inadequate or which made them uncomfortable, hence maintaining their autonomy. None of the participants stopped the researcher during the interviews or refused to answer any of the questions. Participants were also asked if the interview could be tape recorded and if they refused notes were to be taken instead, however none of the parents refused to be recorded. They were also assured that the contents of the tapes would be appropriately destroyed after the final grade of the thesis is issued and until then the tapes will be stored in a safe place under lock and key and only the researcher will have access to their contents.
3.13 Interpretation of data

Simultaneous analysis of both the interviews and observation field notes was done where interpretation of the data with the extraction of main themes was done according to Smith, Jarman and Osborne, (1999)'s interpretive phenomenological analysis, presentation of the data will be in themes and sub themes. Interpretation of these interviews occurred throughout the data transcription.

The interpretative process began with the recognition of assumptions made by the researcher, this is said to be the forward arc of the hermeneutic cycle and the interpretations are considered as the return arc (Crist & Tanner, 2003). Within the hermeneutic cycle interviews, observations, transcriptions and interpretations occur concurrently, always keeping in mind each participant’s story and context (Crist & Tanner, 2003). The hermeneutic cycle involves cycles of reciprocal dialogue between the researchers and the participant of the study. This intersubjective process is not only confined to dialogue with subjects who have experienced the phenomenon, but extends to the representation of the experience in the form of text. With each cycle of the process, I acknowledged my presuppositions and prejudices, thereby leading to further and enhanced interpretation and reinterpretation of the experiences of the phenomena (Sarkar & Cybuliski, 2004).
According to Crist & Tanner (2003), first phase of interpretation involves a critical evaluation of the first interview and observation techniques evident in the transcripts (Maggs-Rapport, 2000). In this phase missing or unclear information was noted so that further exploration was then done in the subsequent meetings. Thus a guide for further inquiry could be prepared (Leonard, 1994); this directed the second and third meetings so that more in-depth and focused data was obtained (Crist & Tanner, 2003).

Further interpretation was done using interpretative phenomenological analysis as described by Smith, et al (1999). In the first step of the thematic analysis each transcript was read several times, anything significant the respondents said was noted down in the left margin (Smith et al, 1999). Emerging theme titles were also noted down in the right margin. The second step involved connecting the emerging themes and identifying the links between them (Smith et al, 1999). In this part frequent analysis of the original transcript was needed to ensure that the themes that were emerging were relevant and representative of what the participants were actually saying (Smith et al, 1999). The main themes identified were then put into a list, each of which having an indication of its place in the transcript (Smith et al, 1999). This process was conducted with all of the interviews, any pending lines of inquiry and clarification of the interpretations and themes identified were addressed at this point and then dealt with when the final meetings were held (Crist and Tanner, 2003). The main themes of each interview were then read together and a main list of themes and sub themes was
merged (Smith and Osborne, 2004). The themes were then translated into a narrative account, where verbatim extracts were used to exemplify each theme clearly (Smith et al, 1999). Care was taken that the researcher’s preconception did not effect the interpretative process thus biasing the interpretation.

The last phase involved the dissemination of the interpretations. Manuscripts with the interpretations were refined; however the interpretation is regarded as an unending process, where the readers of the thesis make the final interpretations (Crist & Tanner, 2003).

The findings of the study are presented and discussed in chapter 4.
CHAPTER 4: FINDINGS AND DISCUSSION

4.1 Introduction and Background data

The aim of this study was to explore the parents’ experiences after their premature infant was discharged from hospital. Roy’s adaptation model was used to give structure and a sense of conceptual consistency to this research study. It was additionally used to give focus for the discussion as well as a basis for the findings (Tolson and McIntosh, 1995).

The data was obtained through the use of semi structured interviews which were conducted with six couples, who had their premature infant discharged at the time of data collection. The first interview was conducted two weeks post discharge and then further clarification and discussion of the interpretations with the participants occurred in another two meetings each two weeks apart. The data collected was then thematically analysed using Smith et al’s (1999) interpretive phenomenological analysis. Main themes and sub themes were identified. These are presented in the next table.
The parents in the sample were aged between 22 and 40 years, most of them lived on their own, except for the youngest couple who lived with the mother’s parents. Three of the couples had other children apart from the premature infant. This factor could be seen as an additional stimulus for these parents. According to Roy’s adaptation model, the parents’ previous experiences with their children are part of the residual stimuli which could help them in their adaptation process. Infact though these parents still felt they needed to be well prepared before their infant was discharged from the Special Care Baby Unit, they also felt that they
were able to take care of their premature infant more and were not as scared as the parents having their first child.

_Brad:_ “ghax kieku kien l-ewwel baby nahseb li ha jkollok biza’ u.......imma la jkollok l-ohrajn taf min xiex ghaddew, allura tkun tista tqabbel...” (Int. 4b line 23)

“because if it was the first baby I think you would be scared.......but since you have the others, you know what they have passed through, and thus can compare...”

One of these couple also had a previous experience at the Special Care Baby Unit, when their first child was also born prematurely at 29 weeks gestation. From the data obtained it was found that even though this previous birth did influence their experiences after discharge, it influenced their experience during the baby’s stay at the Special Care Baby Unit. They felt that they were used to the idea of the Special Care Baby Unit and since their first child had been much smaller and had a lot more equipment they were not so traumatized by their experience in the unit. However, once discharged home their experiences were similar to those of the other parents and they still felt scared.

_Jennifer:_ “...tibza naqra ghal-ewwel....ghax xorta billi kelli lill-iehor qisek tinsa kemm ikunu zghar biex taqbadhom u hekk”(Int. 3a line 24)
"...you are a bit scared at the beginning...even though I had the other one, you sort of forget how small they are to hold them etc"

The premature infants in the sample were born between 31 and 34 weeks gestation. Since the risk of developmental and medical problems is higher with lower gestational ages (Hussey-Gardner et al, 1998), the fact that premature infants lower than 31 weeks gestation were not included in the sample might influence the results. Given that the premature infants did not have life threatening conditions the parents experiences could be influenced, nevertheless, in the study by Padden and Glenn (1997) the effect of having a high risk infant when compared to a low risk infant, did not influence parental stress level. This was also confirmed through the study by Veddovi et al (2001), where even though mothers of well premature infants were recruited for data collection the results were similar to that of the mothers of high risk infants in the study by Holditch-Davis et al (2003).

Their length of stay varied between one and three weeks. This did not appear to influence the parents' experiences and it did not influence the amount of education and preparation for discharge they received. However this cannot be compared to other research since data regarding length of stay was not found through the literature search.
4.2 Themes

4.2.1 "Impact of the Special Care Baby Unit"

Even though none of the parents were asked regarding their experience when their baby was at the Special Care Baby Unit, all the mothers spoke about this experience showing the impact of this aspect in their lives. Infact results from the study by Holditch- Davis and Miles (1995) showed that distressing memories of the birth and intensive care experience were present up to three years. They felt that the period their baby was at the unit was very sad and distressing. This is consistent with the findings of Lau and Morse (2003) where stress levels were very high due to the premature infant’s admission to the Neonatal Intensive Care Unit.

Kate: “tiddispra naqra...tibda tibza li ghandu xi haga...” (Int5a line 105)
“you feel a bit desperate... you’re scared he has something...”

Rose: “...meta qaluli li tieghla l-SCBU, tghidx kemm bkejt, ghax ghalija dahhaltha f’rasli jista’ jmut...” (Int 2b line 40)
“...when they told me that he was going up to SCBU, I really cried, because I had decided that he could die...”

Lucy speaking about Special Care Baby Unit experience: “...it’s shocking...it’s very shocking...” (Int. 6a line 132).
4.2.2 “Loneliness”

An aspect which was very prominent in the data was the loneliness all the mothers felt at the postnatal ward where all the other mothers had their baby and they did not. Charpak et al (2001) and Maroney (2000) emphasize the stress felt by the mothers of premature infants due to their separation from their infants as well as the loss of the anticipated maternal role.

Mary: “...sakemm gibtu id-dar mieghi kont vera mdejjqa, hu hemm fuq, u jien wahdi postnatal” (Int.1a line 10)
“...till I got him home with me, I was very sad, him up there and me alone at postnatal”

Kate: “...qaluli li tieghla fuq mill- ewwel imma xorta thossha ghax tara lil ohrajn ta’ hdejk ...imbaghad anzi tefawni go kamra ma wahda li kellha il- baby l-SCBU ukoll allura konna it- tnejn minghajr il-babies..” (Int.5a line 99)
“...they told me he was going up immediately, but I still felt it because you see all the others near you...at least they took me to a room with another one who had the baby at SCBU as well, so we were both without the babies”
When it was the time that they had to be discharged from postnatal, they felt it was very difficult to leave the baby behind them. It was as if they were abandoning the baby and preferred staying more at hospital rather than going out without the baby.

Rose: “...ma ridtx nitlaq minghajru kienet tkun wisq difficli nigi d-dar u lilu nhallih warajja, preferejt nibqa iktar jien..” (Int. 2a line 13)

“...I did not want to leave without him, it would have been too difficult to come home and leaving him behind, I preferred staying more...”

Lucy: “...u biex nohrog u nhalliha hemm... hrigt nibki...qisni I'm abandoning her..” (Int 6a line 22,25)

“...and to go out and leave her behind... I was crying.. I felt as if I’m abandoning her...”

Jennifer: “thossha li ma gibtiex mieghek....imma kerha li thalliha warajk ta` qisek halleji bicca minnek...” (Int 3a line 19)

“ You feel it that you did not bring her with you...but its dreadful to leave her behind,, it’s as if you left a piece of yourself behind...”

The fathers were not as distressed as the mothers though feelings of stress were still present, however they were more concerned with the fact that they were alone at home without both their wives and babies.
Alex: “jien kont ili gimghatejn wahdi.. bhal speci kelli t-tnejn gejjin lura, minn wahdi kienu gejjin it- tnejn lura...” (Int 2a line 12)

“I had been alone for two weeks, so now both were coming back, from all alone both were coming back…”

Since fathers’ experiences at the Special Care Baby Unit have been limitidley researched, comparison with similar studies cannot be made thus emphasizing the need of further research including both parents, so as to find out about the fathers’ experiences more thoroughly.

4.2.3 “Going home”

All the parents in the study expressed mixed feelings upon the discharge home of their premature infant. These feelings varied from anxiety and fear to happiness and joy. They described having been extremely happy upon being informed on their baby’s discharge.

Alex: “...kont kuntent ha ntir...” (Int. 2a line 14)

“I was so happy I felt over the moon…”

Lucy: “...qisni ha mmur il- genna.....mort qisni rbaht il- lotterija...” (Int. 6a line 18, 20)

“... I felt in heaven...I went there as if I had won the lottery…”
These mixed feelings were also found in other similar studies, the parents greet their infant’s discharge with a mixture of joy and anxiety. The detachment from the security of the hospital environment can be very frightening for the parents (Mancini & While, 2001, Wyly, 1995). Lee et al (2005) found that the withdrawal of the hospital support can cause emotional distress and anxiety. In fact feelings of fear and anxiety were present in all the parents in this study, these feelings were present mainly in the first few days.

Mary: "...tibza naqra ghax l-ewwel lejl wahdek..." (Int 1a line 71)
".....you’re a bit scared, the first night on your own..."

Rose: " ...hassejtni naqra bezghana u nkietata billi qatt ma raqad maghna...fis- sens billi qatt ma raqad mieghi allura bdejt nibza li bil-lejl ma nisimghux..." (Int. 2a line 9)
"...I felt a bit scared and anxious since he never slept with me...in the sense that since he never slept with me I was scared that I would not hear him in the night..."

These feelings of anxiety and fear due to the infant’s discharge home can be seen as a change in the environment of the parents according to Roy’s adaptation model. The word environment in this sense is encompassing the changes, the circumstance and the conditions which are challenging the parents as an adaptive
system (Pearson et al, 1991). The premature infant’s discharge is the focal stimulus in this case, that is the change from having the baby in a safe place, under professional supervision, to home. This requires immediate response to maintain an adaptive state and that is probably the main reason for the feelings of anxiety and fear that were found to occur in the parents in the first few days. These days are the time needed for the parents to adapt to this situation. In this case all the parents had adapted well to the situation and were coping with their baby’s transition home.

*Tom:* “*Jien bzaji ukoll ta ghax kien zghir imma sakemm drafju*” (Int. 5b line 27)
“I was a bit scared because he was small but till I got used to him”

*Lucy:* “*...the first couple of nights were a bit scary, till we got used to her sounds but otherwise ok*” (Int. 6b line 4)

The decrease in anxiety and stress after the first week of being discharged home was also noted by Gennaro in 1988 and Kenner and Lott in 1990. This reduction in stress level was attributed to the fact that the parents have overcome their initial shock and were adjusting to caring for their premature infant at home. This is consistent with Roy’s model and also with the findings in this study. However in other studies such as thoses by Holditch-Davis et al (2003) and Holditch-Davis
and Miles (1995) the mothers experienced stress and anxiety at three and six months after discharge.

The difference in these studies is that the infants in the sample had life threatening conditions, however, this was not shown to cause any difference in other studies since similar results were obtained by Padden and Glenn (1997) and Veddovi et al (2001) where mothers of well premature infants were recruited. The differences in the results could be due to the education received, since in the study by Veddovi et al (2001), mothers who had more accurate knowledge of child development reported fewer symptoms of depression. However, in the other studies the effect of education was not noted thus the results cannot be compared.

In this case the parents' adaptation level was also influenced by the contextual stimuli, which are the peripheral factors that influence the situation. These factors will also affect how the parents' deal with the focal stimuli. Factors such as education and hands on practice received prior to discharge were found to be very important in easing the parents' adaptation process, this will be discussed in the next themes. Another contextual stimulus which increased the parents' fear and anxiety was the removal of any monitoring the child had at the Special Care Baby Unit. The monitors used to give the parents a feeling of safety, now that their infants were without any monitoring they were scared that something might happen and they would not notice.
Rose: “...hemmhekk drajna li jekk ma hax nifs daqqitli l-alarm....imma mbaghad hawn ma kellu xejn...” (Int. 2b line 22)

“....there we were used to the alarm buzzing if he did not breath...but then over here he had nothing...”

The residual stimuli which have developed from previous experiences have been already discussed before and these were considered to be the experiences three of the couples had with their previous children which helped them to adapt to their premature infant’s arrival home better than the parents whose premature infant was their first born.

Another concept which caused fear and anxiety in most of the parents in the study was their concern about their ability as parents.

Rose: “...tibda tigi f’dubju jekk ha tkunx kapaci...” (Int. 2a line 28)

“...you start having doubts if you will be capable...”

This is included in the self concept mode of Roy’s model, and it encompasses the way in which a person sees oneself in society (Akinsanya, 1994b). The ability of being parents is part of the personal self of these parents, since they would have a self ideal they would like to achieve. The ability of being parents was also mentioned by Hummel (2003), as being a significant concern of parents of premature infants.
In the first few days they might find it a bit difficult to obtain this self imposed ideal and this might cause fear and anxiety, however as they got used to the baby their ability as parents became more efficient. Thus the difficulties in this area decreased, concurrently decreasing the anxiety and fear related to this concept. Infact the parents in the study were mainly scared about the parenting aspect of having their baby home in the first few days, such as handling the baby, not hearing the baby at night and caring for the baby well.

Mary: “tibda tibza naqra ahna 1-ewwel baby u qatt ma hadna hsieb tfal allura sakemm tidra tibda tibza taqbu...imm issa drajna” (Int. 1a line 16)

“You’re scared a bit, for us it is the first baby and we never took care of children before so till you get used to him, you’re scared of holding him...but now we got used to it”

Rose: “...kont nibza li ma nisimghux bil-lejl allura ma nqumx...” (Int. 2b line 22)

“...I was scared that I won’t hear him during the night and so I would not wake up...”
4.2.4 “Tiredness”

Having the baby home required the parents to adapt and learn how to cope with this challenge in their life. A main concept that emerged once the baby was home was that of tiredness. The parents all mentioned that they were feeling very tired due to lack of sleep since their babies were waking up often during the night.

Joe: “...dik li ma torqodx sew ghax mhux ta` darba, ta` kuljum, tkissrek”
(Int. 1b line 68)
“...the thing that you don’t sleep well, because it’s not a one off thing but everyday, it tires you out”

Angelina: “qed nispicca nghajja hekk...ta` kuljum titbazwar...” (Int 4b 62)
“I’m ending up getting tired...this thing of everyday wears you out...”

Alex: “...ghal-ewwel lanqas stajt inqum filghodu” (Int 2b line 24)
“...at first I could not wake up in the morning”

This has been also shown in the literature, and taking care of a premature infant has been associated with parenting difficulties (Davis et al, 2003). Premature infants though they tend to sleep more total hours than a term infant, their sleeping pattern is very erratic and they tend to wake up more often (Trachtenbarg
& Golemon, 1998). In fact in the study by McLean et al (2000), mothers of premature infants reported to have lower levels of energy.

4.2.5 “Coping at home”

However, the parents in the sample have been trying to cope with this tiredness and most of them have been sharing the night between them so as not to get too tired.

Joe: “...inqumu darba kull wiehed biex ma nbatux hafna ghax hekk ghal l-ingas mhux bhall tqum il-lejl kollu wahdek, difficli.." (Int 1a line 26)

“... we wake up alternately so we don’t suffer too much because at least like this you don’t wake up all the night on your own, it’s difficult...”

In a couple of cases they opted to change to bottle feeding during the night so that the baby sleeps more and they get less tired.

Alex: “l-ewwel li waqfitu bil-lejl (breastfeeding) ghax bil-lejl ittieh u siegha wara jerga iqum, ma tistax toqghod sejjer hekk, lanqas konna nfitlu inqumu ghax tispicca ma torqod xejn...” (Int 2b line 31)

“At first she stopped it during the night because she used to give him and an hour after he wakes up again, you can not keep on going like that, we were too tired to wake up because you end up not sleeping at all...”
Since breast feeding is considered to be very important especially for preterm infants, the mothers felt an obligation to breast feed and when breast feeding was stopped so they could cope with the situation they felt very guilty. This guilt could be due to difficulties in the self concept mode, where the mothers had a self ideal that they would be breast feeding their infant as well as a moral- ethical obligation to breast feed their infant for his or her benefit. Having to abandon this ideal would cause anxiety and guilt until they accept the idea, which was clearly shown from the data obtained.

Mary speaking about breastfeeding: “ippruvajt imma m’iniex inlahhaq...m’hemm x’taghmel inhossni guilty...imma issa irrasenjajna ruhna...” (Int 1a line 32)

“I tried but I’m not managing... there’s nothing to do, I feel guilty...but now we accepted it...”

How the parents cope with this situation was noted to be influenced by a number of factors which will be discussed next. These factors can either hinder or support the parents in their adaptation process and thus can help the parents to cope with the discharge of their infant from hospital or else confuse them more.
4.2.6 “Knowing the baby”

All the parents in this study felt strange caring for their baby during the first few days, and they said this was because they had to get to know the baby. This is consistent with the literature where Hoffman (2005) stated that parents have to learn how to deal with their infants, as well as with the findings of Brady-Fryer (1994). The mothers in the study felt that they had to get to know their infants all over again, as well as having to learn their infant cues and behaviour. This was also mentioned in the present study where the parents said that they had to learn the reason why their baby was crying. Once they achieved this they felt they could cope more as they were not worried about their baby’s cries unless they recognized it as being different from the usual cries.

Kate: “...tinduna il-bikja kif tkun...” (Int 5b line 45)
“...you recognize how the cry is...”

Rose: “...gurnata b’ gurnata tibda tifhem igtar ghalsiex qed jibki jekk hux bin-nghas, jekk hux bil-guh...” (Int.2a line 9).
“...day by day you understand more why he’s crying, if he’s sleepy, if he’s hungry...”

Ben: “...jekk tibda tibki igtar mis-soltu hemm tinkwiera ghax il-bikja tidraha...” (Int. 3a line 49).
“... if she starts crying more than usual you get worried, because you get used to her cry...”

They had also started to recognize the baby’s behaviour, and get into a routine. Signs of colic or constipation were also being recognized. However, they have learnt how to cope with these problems from the Special Care Baby Unit which is the next theme, that is, through education and practice.

4.2.7 “Education and practice”

The role of both education and practice was found to be very important in helping the parents adapt and cope with their infant’s discharge home. Lau and Morse (2003) stated that the premature infants’ parents’ stress levels decreased because since they spend a longer time in hospital, they are more trained in caring for their babies and end up being more competent care givers than term infant parents. Parental anxiety after their infant’s discharge may emerge from a lack of knowledge of how to care for their infant as well as lack of experience of caring for their infant (Kenner & Lott, 1990). Thus education about the child’s care is very important to ease the transition from hospital to home. This was clearly shown in the data acquired in this study.
In fact most of the parents in this study have emphasized the importance of the education they received and the experience they accumulated, to help them cope with their baby at home.

Rose speaking about the transition from hospital to home: “...imma ma kienitx daqshekk difficli ghax hemmhekk ghallmuna hafna affarjiet qabel hrigna allura thossok preparata” (Int.2a line 9)

“...but it was not so difficult because they taught us a lot of things over there before we came out so you feel prepared”

Alex: “Pero’ qed nghidlek il-fatt li ghamel gimghatejn hemmhekk, ghena hafna anke lilna”(Int.2a line 38)

“But I’m telling you the fact that he did two weeks over there, helped even us a lot”

Tom: “...ghax jispjegawlek kollox ... u ma kellniex problemi wara li hrigna, ma sibniex diffilkultajiet...” (Int.5a line 71)

“...because they explain everything... and we did not have any problems after discharge, we did not have any difficulties...”

Positive effects of education have been documented in the literature, such as the results obtained in the study by Meyer et al (1994), where mothers who received a good education prior to discharge showed less depressive symptoms, had a better
parent-infant interaction and had less feeding problems. The importance of practice was also emphasized in the literature, the more the parents’ care giving competencies are developed through practice while the baby is still hospitalized, the better they can cope when they are at home (Pridham et al, 1995).

Most of the parents in this study emphasized how much the experience they had acquired at the Special Care Baby Unit and the education they received helped them to be able to take care of their infant at home. The parents whose premature infant was their first baby knew nothing about taking care of the baby and they learnt everything at hospital. They were taught how to change a nappy and how to handle, wash and feed the baby. However, the importance of practice and education was also accentuated in the parents who had other siblings as well.

*Rose:* “...*fghin hafna, meta tghamel l-affarjiet int li vera titghallem ghax hekk tidra...*” (*Int. 2a line 60*)

“...it helps a lot, when you do things yourself that you really learn, because that’s how you get used to do them...”

*Tom:* “...*jien huma ghallmuni naghtih bottle u inbiddilu jigiefiri ghax qabel ma kellix ideja...*” (*Int. 5a line 62*)

“...they taught me how to give him a bottle and how to change him, because I did not have an idea...”
Jennifer: “...tibza naqra imma hemmhekk jghallmuk kif ghandek tahsilha, kif ghandek taqbadha meta tkun zghira. Ghax xorta billi kelli l-iehor qisek tinsa kemm ikunu zghar...” (Int.3a line 24)

“...you’re scared a bit, but over there they teach you how to wash her, how to hold her when she’s small. Because even though I had the other one, you sort of forget how small they can be...”

Only one of the couples had experienced rooming in, that is spending a night at hospital with their baby in a special room. Although they are on their own in this room there is the support of the Special Care Baby Unit around the corner and the parents can phone directly at the unit if they need any help. This was found to be very useful by the couple who experienced it, and another couple said they wished they had done it but at the time they were anticipating going home too much to appreciate its importance. The usefulness of rooming in was also mentioned in the literature, so that the parents gain some hands on experience with professional support close at hand (Antunes & Spear, 2003).

Joe: “...il-iejl specjalment tkun taf li hemm xi haga u jkollok bzonn issaqsi ikun hemm in-nurses hemm, kemm iddoqg u jwiegbuk, le tajba dik ghax qisek tidra...” (Int.1a line 68)

“...especially during the night, if anything happens and you need to ask something, there are the nurses there, you just have to ring and they answer you, no it’s a good thing so you get accustomed...”
Rose: "...ahna hrigna malli t-tifel gie discharged mill-SCBU ahna hrigna mill-ewwel id-dar. Vera dak iz-zmien ikollok genn biex tigi id-dar, imma nahseb li kieku ghamilt lejl imma hu hdejja...fis-sens jekk jiena ghandi diffikulta u l-iktar li tbezzani ta’ bil-lejl hemm xi hadd..." (Int 2a line 49)

"... we went out as soon as the baby was discharged from SCBU, we left for home immediately. It’s true that at that time you are dying to go home, but I think if I did a night with him beside me...in the sense that if I have a difficulty, and I was mainly scared of the night, there is someone..."

One of the couples felt that they did not need any education or practice because they had other children and felt that from the previous experiences they knew all that there was to know.

Angelina: "...jiem peress li kell li dawk it-tfal l-ohra ma kellix ‘as such’ bzon li jippreparawni ghax qisni kont diga` naf..." (Int.4a line 54)

"...Since I had the other children I did not really need to be prepared, because I already sort of knew..."

Brad: "...ahna konna nafu x’ghandna nghamlu u hekk, staqsewna irridux inbiddlu in-nappy...imma minhabba il-wires ma xtaqniex u diga konna nafu..." (Int. 4b line 39)
“...we knew what we had to do, they asked us if we wanted to change the nappy...but we did not want to because of the wires and we already knew...”

However, in the data obtained from their interviews they still had some queries and felt a bit scared to handle the baby. Thus showing the importance of education even in cases where the parents think they do not need it.

Brad: “...tiddejjaq taqbu naqra, tibza li ha tghamillu xi haga...” (Int. 4a line 61)
“...it’s a bit uncomfortable to handle him, you’re scared you’re going to hurt him...”

Brad: “...meta nigu biex nibdewlu l-ikel, qisek ma tkunx taf ezatt meta...” (Int. 4b line 25)
“...when we have to start giving him food, you somewhat don’t know exactly when to start...”

On the other hand, though education and practice are very important in helping the parents to cope, the information given needs to be consistent and given from reliable sources. In one of the interviews it was mentioned that information giving was different between staff. It was noted that important information regarding the baby’s health was given to a mother and not to the participant of this study.
Lucy: "...kien hemm wahda hdejja bil-baby u kien hemm midwife qed tkellimha u tawha hafna iktar informazzjoni milli taw lili" (Int6a line 165)

"...there was a lady with the baby near me and the midwife was talking to her and she was being given much more information than I had received"

Lucy: "...lil din bdew jghidulha li lil baby ma tistax tuzalu quilt ghal sena, lanqas kont naf...u biex il-baby ma taghmiliex il-fuq tal-cot...din qatt ma kont nafa" (Int.6a line 183)

"....they were telling her that she can’t use a quilt for the baby for a year, I did not know...and not to put the baby high up in the cot... I never knew this"

The information that was given to the other mother was information to decrease the possibility of sudden infant death from occurring, however, since Lucy was not given this information, she was very worried. As she had heard only part of the conversation she did not know the reasons for these instructions and was very anxious that she did not do so in her first baby. Thus, it is important that a policy regarding information giving is created so that all the parents are given the same information and that no useful information is neglected. The nurses and midwives’ knowledge should also be assessed because certain information might not be given because it was not known. Thus further research should be directed towards assessing the knowledge of the staff working at the Special Care Baby Unit.
Another source of information which was found to cause a lot of anxiety in the participants of this study was information given from unreliable sources and hearsay from unprofessional people. Results from this study showed that it caused anxiety and fear about the baby’s well-being as well as confusion and uncertainty about what actions to take.

Joe: “...min jghidlek prova halib differenti ghax dak il-halib qed iqabdu il-gass, iktar tithawwad...” (Int. 1b line 9)
“....they tell you to try a different type of milk, because it’s that milk that is giving him colic, they confuse you more...”

Rose: “...ghax tal-familja min jghidlek mod, heqq il-genituri taghna, omm dan ilha tletin sena u ommi ila dsatax ma jkollhom tfal zghar jigifieri certu affarjiet tal-mentalita' taghhom iggennuk...” (Int. 2b line 44).
“....because from the family they tell you one thing, our parents, his mother for thirty years and mine for nineteen have not had any small children, so they have a certain mentality for certain things, they drive you crazy...”

Alex: “...ikollhom hafna tejoriji taghhom, u iktar iggennuk ghax min jghidlek haga u min jghidlek ohra u iktar tithawwad...” (Int. 2b line 45)
“...they have their own theories and they confuse you more, who tells you one thing and who tells you another and you get more confused...”
Therefore, it can be seen that information can be either a positive or a negative contextual stimulus depending on the source from where it is coming and depending also on its consistency. According to the results from the study, locally, information giving as well as preparation for discharge is adequate and the parents are mostly satisfied with the information they have been given. What would make this discharge planning more consistent so that all the parents receive similar information and no useful information is omitted, would be a policy stating all the information required by the parents whose infants are being discharged from the Special Care Baby Unit.

Another important aspect which helps parent to cope with their infant’s discharge home is the support they receive from both the hospital and their family.

4.2.8 “Support”

In Roy’s adaptation model, support would influence the interdependence mode, which involves the balance between independence and dependence on others (Fawcett, 1995). In this study all the parents seem to be accepting well their dependence on others for the time being. However, this may start to become a problem later on when they become confident in caring for their baby and are managing their time well.
In the study by Morawski Mew et al (2003), it was found that depressive symptoms decreased when social support was available. Lack of social support was also related to higher levels of distress in the study by Vanderberg (1999). In the present study all the parents had received support from their respective families, in Malta families are rather united and this was shown in this study since all the parents had received all the help they needed from their families. Help was given in terms of both physical and psychological support. Relatives were reported to help in housework, cooking and shopping as well as just for company, and someone to talk to. The support they received helped the parents in coping with the situation since they had more time available to care for their baby.

Lucy: “Mill-familja hafna sibna support, il-mummy kienet tigi, anke bhala kumpanija...” (Int 6a line 97)  
“We found a lot of support from the family, my mum used to come, even as company...”

Jennifer: “allahares ma jkunux huma, ghax vera insibhom, ommi u ommu dejjem gejjin jaraw ghandiex bzonn xi haga, anke xiri u hekk...” (Int. 3a line 54)  
“Thank god it was for them, because they really help, my mother and his mother they are always coming to see if I need anything, even just shopping...”
Mary: “...ommi u ommu tghidx kemm qed jghinuna, kuljum ikumu hawn, inaddfuli u jixtruli l affarjiet li jkolli bzonn, imbaghad ommi issajarli, jien xoghli niehu hsieb il-baby...” (Int. 1a line 47)

“...my mother and his mother are really helping us a lot, they are here every day, they clean and buy me the things I need then my mother cooks, my job is taking care of the baby...”

Support from hospital was also mentioned to be quite important, this included the normal MMDNA visits which each mother receives postnatally, as well as the knowledge that they can phone the Special Care Baby Unit at any time and they will get answers for their queries. This is confirmed in the literature, where the knowledge that support and advice are available was found to facilitate the transition from hospital to home as well as decrease parental stress (Emmanuel & Knight, 1999).

Rose: “...ta l isptar jibghatu ta l-MMDNA u sibnjha jigifeiri ghax hi stess tistaqsik ghandekx xi mistoqsijiet li trid tistaqsi...” (Int. 2b line 42).

“...they send the ones from MMDNA from hospital, and we found it useful, since she asks you herself if you have any questions you need to ask...”

Joe: “...u anke issa naf li jkolli bzonn xi haga naf li nista incempel il-gurnata shiha, naf li dejjem ha nsib min jghini...” (Int. 1a line 54)
“...and even now, I know that if I need something, I know that I can phone throughout the day, and I know that I will find somebody to help me...”

Angelina: "..ghax dan jekk jinqalalek xi haga, taf li dejjem tista iccempel ghax qalulna..." (Int. 4b line 42)

“... because even if something happens, you know that you can phone always, because they told us...”

The use of home visits was suggested to be successful in decreasing stress and increasing parents’ coping abilities (Edwards, 1994). However, the parents in this study did not think they needed follow up care by nurses from the Special Care Baby Unit, for them having the telephone number and knowing they can phone at any time was good enough.

Kate: “Jekk ikolli bzonn xi haga incempel jigifieri ma nabsibx li hemm bzonn iktar ghax la jkollok lil min tikkuntattja bizzejd hux” (Int. 5a line 79)

“If I need anything I will phone, so I do not think there is the need for anything else, since you have someone to contact, it is enough”

On the other hand, when doing the interviews all the parents had queries about aspects of their baby’s care, mainly concerning the baby’s health and well being, showing that if follow up care was available they would probably benefit from
such a service. Thus further research should address this area so as to maximize the benefit these parents can receive from hospital.

The baby’s well being was a very worrisome factor for all the parents and any anxiety, uncertainty and fear that was present stemmed from a perceived lack of well being for the baby. This is in fact the ninth theme which emerged from this study.

4.2.9: “Baby’s well being”

The infant’s health and well being was found to be the parents’ major concern in this study. This was also shown in a number of studies, such as in the studies by Holditch-Davis et al (2003) and Falleiros Mello et al (2002). In these two studies fear about the babies’ health was also present. This was also confirmed in the studies by Lee et al (2005), May & Hu (2000) and Moon (2000, 2002) as cited in Lee et al (2005), where mothers of premature infants had more concern about their infant’s health. It was noted that the perception of the possibility of ill health influenced the parents’ emotive state and caused fear and anxiety. Apart from this all the parents modified their behaviours and had to do some changes in their life style for the baby’s well being. These issues will be discussed in the following sub themes.
“A cause of anxiety and fear”

Colic and constipation were then main issues that caused anxiety and uncertainty in all the parents. Even though they declared that they knew the reasons for their babies pain and cries, they still were very worried and were trying to do everything they could to help their baby. They had been taught at hospital how to help the baby when he is constipated, that is, to apply a specific gel. The fact that they had a way to help the baby was useful in decreasing a bit their anxiety, However, they still were a bit stressed that the baby had to suffer.

Alex speaking about constipation: “...trid tghinu fiit ghax inkella jkun mugugh, allura meta naraw li qed ibati nghamlulu il-gel u mil-ewwel jahdem imbaghad.” (Int 2a line 64)

“...you have to help him a bit because if not he would be in pain, so when we see him suffering we apply the gel and it works immediately.”

The parents, though aware colic cannot really be prevented still were very worried and were trying to do everything possible to help the baby. They were seeking opinions from every possible source and using different methods to try and prevent colic as much as possible, such as using special bottles, changing the milk, keeping the baby warm and using anticolic treatment. However these methods did not eliminate the colic problem and thus caused more anxiety in these parents.
Mary: “Anke qed ibati bil-gass, ikun rieqed u jaqum jibki mugugh, ittih wega’ f’daaqqa, ma nafx x’naqbad nghamillu miskin, ghax imlibbes sew, inzommu shun kemm jista’ jkun...” (Int. 1a line 21)

“He’s even suffering from colic, he’d be asleep and wakes up crying and in pain, he’s in pain suddenly, I don’t know what I can do, because I dress him up well and keep him warm as much as possible...”

Mary: “...jibda jibki imbaghad jieqaf f’daaqqa, jidher li bil-gass imma xorta tinkwieta naqra u ma nixtieqx li jkun mugugh...” (Int. 1b line 12)

“...he starts crying and stops suddenly, it shows that it is colic, but still I am a bit worried, I wish he will not be in pain...”

Angelina: “… naqra gass ghandu issa, imma dak ma tantx tista’ tevitah, qed nghamlu li nistghu ta imma xorta baqa’ jbat...” (Int. 4b, lines 6)

“… he has a bit of colic, but that can not be avoided really, we are doing what we can, but he’s still suffering...”

Brad: “ Biddillnilu il-bottle ghamilnilu bottle iehor ghax qalulna li ahjar din id- ditta, qeghdin apposta biex ma jqabbadhomx gass...” (Int. 4b, line 8)

“We changed the bottle, we are using another bottle, because they told us that this brand is designed to prevent colic...”
Research has documented consistently the risk of premature infants for having developmental disabilities (Blackburn, 1995, Kessenich, 2003, Lee et al, 2005), however in this study most of the parents were not aware of this possibility and saw their babies' future like that of other children. Only one mother was aware of any potential problems and this might have been because she worked in the area of psychology. This is not consistent with findings from other research studies, where the mothers were aware of the possibility of developmental problems and this caused anxiety and fear (Lee et al, 2005, Vedovini et al, 2001). This lack of awareness might cause problems later on in life if the child exhibits developmental disabilities because the parents would not be expecting it.

A poor immune system is also common in premature infants and this makes these babies more prone to infections and re-hospitalizations (Antunes and Spear, 2003, Blackburn, 1995). In fact one infant in the sample had already been re-hospitalized due to bronchiolitis.

Jennifer: "...ghadna kif kellna t-tifla l-isptar, kienet Disneyland, ghamlet gimghat hemm ghax kellha bronchiolitis." (Int. 3c line 4)

"...the girl had been in hospital, she was in Disneyland, and she was there for a week as she had bronchiolitis."

Most of the parents were aware of this probability and had to prevent this as much as possible by changing their life style.
“Changes in Life”

The reason for the changes that the parents in the sample had to undergo, was the baby’s well being. Most of the parents were not going out as much as possible, the fact that the study occurred during winter also influenced this since due to the weather being rather cold the parents were also less likely to go out. They also tried to avoid crowded areas and also having a lot of visitors at home, to prevent a lot of people breathing on the baby and thus the possibility of the baby getting an infection. Some of the parents also mentioned avoiding cigarette smoke as much as possible and smoking in doors was not allowed.

*Lucy:* “...it-tejn li ahna konna wary li ma jigux nies minhabba infections...” (Int. 6a line 83)

“...both of us were very cautious that people did not visit, due to infections...”

*Fred:* “...ma xtaqniex li jigu hafna nies id-dar fil-bidu, hafna nifsiyet fuqha...mhux tajjeb hux...” (Int. 6a line 84)

“...we did not wish that a lot of people come at home at first, a lot of breathing over her...it is not good eh...”

*Jennifer:* “...trid toqghod naqra attenta, one issa x-xitwa...b’din il-kesha zgur mhux se nabbuzaw nohorgu biha, allura qisek toqghod gewwa iktar...”
mis-soltu. Jekk tara lil xi hadd ipejjep tipprova ma tmurx hdejh ghax qisek toqghod iktar attenta ...” (Int. 3a line 39)

“...you have to be a bit careful, first of all now that it is winter...with this cold we are not going to dare go out with her, so you end up staying inside more than usual. If you see somebody smoking you try avoiding going near him because you have to be more careful…”

Brad: “...anke jien ma npejjipx hodejha... tipprova tevitalha kemm tista’...” (Int. 3b line 40)

“...even I do not smoke near her... we try to avoid as much as possible…”

Mary: “... mhux se nohorgu ghalissa zgur, l-ewwel nett il-bard u lanqas kieku ghadu wisz zghir ma jmurx jaqbu xi haga...anke toqghod tiltaqa ma hafna nies u hafna nifsijet, ahjar le...” (Int. 1a line 50)

“...I am not going to take him out for now for sure, first of all it is cold and he’s still to small, so he won’t get sick... even you stay meeting a lot of people, they stay breathing on him, better not…”

Some of the mothers also felt that they had to stop working so as to take good care of their baby themselves. They felt that they wanted to spend the most time possible with the baby and not leave him with the grandparents even though it was a strain economically.
Rose speaking about stopping from work: “...bhala finanzi qed tidhol paga wahda bis, allura dejjem qisek trid tara, pero' giet vantagg taghna ukoll ghax fis-sens qed inqattghu hafna hin mieghu...differenti milli kieku qieghed man-nanniet...” (Int.2b line 14)

“...financially, we have only one pain, so we have to be a bit careful, but it was also an advantage in the sense that we are spending a lot of time with him... it is different then if he stayed with the grandparents...”

These changes could affect the role function mode in Roy's model, mainly the secondary role, where the mothers had to change their working role and only take care of the baby. Tertiary roles could also be affected, because the parents in the sample were not going out like before, thus any hobbies and activities they used to do before had to be decreased or stopped completely. Changes in these roles may cause difficulty until mastery of the new role occurs. Stress may be present due to changes in these roles the parents had to undergo.

In fact these changes were sometimes perceived by the parents as sacrifices they had to do for their baby and thus caused some stress. Nonetheless, in most of the cases the parents had accepted these changes and they were seen as normal behaviour for all parents.

Mary: “Xbajt gewwa ta ghax ilni...imma m’hemmx x’tghamel...” (Int. 1a line 52).
“I am fed up staying inside…but there’s nothing to do…”

Kate: “Kultant jien jaqbduni naqra dwejjaq ghax jien wahda li id-dar ma noaqghodx hlief biex norqod u ninhasel, il- bqijja il- hin kollu barra altura bhal speci...anke filghodu wahdi hawn…” (Int. 5a line 93)

“I was feeling a bit sad sometimes, because I am a person who used to stay home only to sleep and wash, otherwise I was all the time out, so now it’s sort of…even in the morning all alone here…”

Jennifer speaking how changes affected them: “Ijhem xejn kbir din xi haga normali li kulhadd jghamel meta jkollu baby imma il-bqija...xejn ta barra minn hawn…” (Int. 3a line 42)

“It is no big change, it is a normal thing everyone does when they have a baby, but otherwise…it is nothing extraordinary…”

Nevertheless, in all the cases the baby was seen as worth all the trouble and sacrifices they had to do because now the baby and his/her well being was their priority.

Joe: “...tara lilu tinsa kollox...tghid worth it-trouble kollu...” (Int. 1b line 97)

“..once you see him you forget everything...you say it is worth all the trouble…”
It can be seen that the parents’ experiences are affected by their baby’s well-being, knowing how to cope with the baby’s needs and with the problems they might meet, helps the parents in having a positive experience. Receiving a good education and good preparation while at hospital helps the parents cope better with these aspects. This is also helped by having a good support network when at home.
CHAPTER 5 CONCLUSIONS

The aim of this study was to explore the parents’ experience after their premature infant was discharged home. Roy’s adaptation model was used to give structure, conceptual consistency, a focus for the discussion as well as a basis for the findings. Six parents of premature infants participated in this interpretive phenomenological study. Data collection was done through the use of interviews, and later thematically analysed used Smith et al (1999) interpretive phenomenology analysis method.

Nine themes emerged from this data analysis, these are “Impact of the Special Care Baby Unit”, “Loneliness”, “Going home”, “Tiredness”, “Coping at home”, “Knowing the baby”, “Education and Practice”, “Support” and “Baby’s well being”. The influence of the self concept, role function and interdependence mode, as well as the focal and contextual stimuli in Roy’s model were discussed as a basis of these findings.

The impact of the Special Care Baby Unit on the parents’ life was evident in the data collected and was emphasized by the parents themselves. Loneliness felt at the postnatal ward was also a prominent aspect in the data. In the theme “Going home”, the mixed feelings the parents were having were discussed. Parents were feeling fear and anxiety as well as happiness that their infant was going home. The negative feelings were mainly due to lack of monitoring and withdrawal of
hospital support. Another factor causing the participants concern was their ability as parents. The feeling of tiredness in the first weeks after discharge was evident in all the parents in the study. This was mainly due to the erratic sleep patterns of their premature infants. Nonetheless adaptation to these situations was evident in the information obtained. The parents in the study seem to be coping rather well with the situation. They were noted to start to adapt better to their situation once they got to know their baby's behaviour and routine. Other factors which were noted to influence the parents' coping ability were the education and hands on practice they received at the Special Care Baby Unit, this is in fact another of the theme which emerged in this study. In many cases these were said to be beneficial, however, it is important that the information given is consistent and is given by reliable sources. Information given from unreliable sources or hearsay, as well as a lack of information was found to cause anxiety in these parents.

Another important aspect which eased the parents' transition from hospital to home was the support they received from hospital and their families. Follow up care was not believed to be required since having a contact number for emergencies and any queries was considered to be enough. On the other hand, all the parents had questions about their baby's care, implying that follow up care might in fact be beneficial.

The last theme which was discussed in this study was the baby's well being, this was found to be the parents' main concern and was found to be a cause for
anxiety and fear. These feelings mainly centered on the problems of colic and constipation and a fear that the baby might get sick. This made the parents undergo certain changes in their lives to protect the baby as much as possible. These changes included, staying indoors, avoiding crowded areas, and not having visitors home. These changes though they sometimes caused stress but were accepted by most of the parents as a normal aspect of parenthood.

5.1 Limitations of the study

Owing to the small sample size results cannot be generalized to the whole population of parents having preterm infants at the Special Care Baby Unit. However, generalisability was not a priority in this study since it is not the aim of phenomenological research. The aim of such a research study was to explore the experiences of the parents under study so as to understand their reality and from the data obtained further research could be then initiated.

Apart from the anticipated methodological limitations, which were discussed in chapter 3, further limitations could be identified following this study’s completion. Infants below thirty one weeks were not included in the sample. Since the risk of developmental and medical problems is higher with lower gestational ages this might influence the results obtained.
Since all the interviews were conducted in Maltese, the excerpts had to be translated in English. The limitation with translating these, was that some Maltese expressions could not be literally translated. Care was taken that the meaning of the translated interviews was not distorted. To ensure that the translations were correct they were checked by a professional experienced Maltese lecturer.

Another limitation is the short follow up period which was only six weeks, adaptation could have been explored better along a longer period as well as any developmental or medical problems that might have emerged at a later stage. In spite of the limitations the results obtained are important in showing the current discharge plan situation locally as well as this group of parents’ experiences of their infants’ discharge home. From the data gathered recommendations and implications for research and practice are suggested.

5.2 Implication for practice

Parents’ experiences showed that discharge planning locally though satisfying can sometimes be inconsistent, this implies that:

- There is a need for a standardized protocol to be prepared stating the discharge education to be given to these parents as well as the care aspects in which they need to achieve competency.
- There is also a need to examine the education, knowledge and competence of nursing and midwifery staff in preparing the parents for discharge.

- Appropriate training is required to enable nurses and midwives to give more consistent discharge information.

The establishment of a follow up care service for all infants discharged from the Special Care Unit might also be of importance in helping parents cope with the transition from hospital to home.

5.3 Recommendations for research

- Further research also needs to address both parents’ experience of the Special Care Baby unit locally since through this research it was found that the experiences parents have a direct impact on their lives.

- A quantitative study needs to follow this qualitative study to look at this aspect more holistically as well as making the results more generisable.

- More research could also be done exploring the Special Care Baby Unit staff’s experiences of discharge planning so as to gain their perspective in this aspect.
- Further research could also be done to explore parents’ experiences after their premature infant is discharged home, when the premature infants are below 31 weeks gestation so as to compare the two different experiences.
REFERENCE LIST


- NAWww.umassmemorial.org/ummc/hospitals/med_center/services/NICU/glossary.cfm


APPENDIX NO. 1

Theoretical Framework: The Roy Adaptation Model

Nursing models used for research studies give structure and a sense of conceptual consistency based on what is already known, it also gives focus for discussion as well as a basis for the findings (Tolson and McIntosh, 1995). Nursing models not only guide the researcher’s understanding of what the natural phenomena are but also a reason for their occurrence (Polit and Hungler, 1999). However it is important that the choice of a model is appropriate, the nature of the problem being explored would determine the type of model to be used in guiding the investigation (Akinsanya, 1994a).

The nursing model considered to be most adequate for this particular research is the Roy adaptation model. Hedberg Nyqvist and Sjodén (1993) state that this model is ideal for identifying stimuli leading to adaptive and maladaptive behaviors in parents and can serve as a care plan. The present study will be exploring parents’ experience following discharge of their premature infants, the parents’ adaptation level to this big change in their life can be indepthly explored and factors influencing adaptation can be identified. The use of this model in this research is important because the model supports the promotion of adaptation. It explains how the adaptive processes affect health and it helps to predict the effects of nursing interventions on adaptive life processes and functions (Akinsanya, 1994 and Fawcett, 1995).
Adaptation relates to the way a group or individual respond to changes in the environment (Akinsanya, 1994b), it is 'the temporary or permanent changes in structure, function, behavior or culture that enable an individual or group to survive in a particular environment' (Beland, 1981 as cited in Castledine, 1986). Roy develops this theme of adaptation and adapts it to nursing. This model uses an approach which focuses on individuals who may be experiencing difficulties in coping with the changes in their lives (Akinsanya, 1994b), which could be the case for the parents of premature infants when they are discharged home.

Roy’s model was developed in America in 1964 and was first put in use in a degree program in Mount St. Mary College in 1968 (Chadderton, 1986 and Pearson, Vaughan and Fitzgerald, 1996). Throughout the years Roy has developed the theory, progressively including a humanistic and holistic view of the person (Pearson et al, 1996). The model is both inductive and deductive combining concepts based on the systems theory as defined by Von Bertalanffy, with concepts from the adaptation level theory from psychophysics where Helson (1964) defined adaptation as a process of responding positively to environmental changes and described the three types of stimuli used in Roy’s model discussed below (as cited in The Roy Adaptation Model, n.d., Fawcett, 1995, McKenna, 1997, Pearson et al., 1996 and Tolson & McIntosh, 1996). The view of the person as an adaptive system took shape from the early works of Dohrenwend, Lazarus, Mechanic and Seyle (The Roy Adaptation Model, n.d).
Roy has presented the philosophical claims underlying the model in the form of scientific and philosophical assumptions reflecting holism, affinity, control processes, activity, creativity, purpose and value (Roy, 1987 as cited in Fawcett, 1995). The philosophical assumptions of Roy’s model include several values and principles of humanism (Fawcett, 1995). The philosophical assumptions are that a person:

- uses creative power
- behaves purposefully and not in a sequence of cause and effect
- possesses intrinsic holism
- strives to maintain integrity and relationships.

(Fawcett, 1995, and The Roy Adaptation Model, n.d.).

The scientific assumptions were drawn from the systems and adaptation level theories, these assumptions are:

- The person is a bio-psycho-social being.
- There is a constant interaction between a person and a changing environment needing adaptive responses.
- Persons use both innate and acquired mechanisms to cope with a changing world which are biological, psychological and social in origin.
- Health and illness occur in a continuum and are inevitable in a person’s life.
- Environmental changes require a person to adapt.
- A person’s adaptive response is a function of the level of adaptation achieved.
• The person's adaptation level comprises a zone indicating the range of stimulation that will lead to a positive response.

• There are four modes of adaptation, physiologic needs, self-concept, role function and interdependence relations.


Modes in Roy's Model

The **physiological mode** emphasizes the maintenance of physical and physiological integrity of the adaptive system (Fawcett, 1990, Fawcett & Tulman, 1990); it is concerned with the structure and function of the body (Akinsanya, 1994b). The maintenance of homeostasis depends on the interaction of different body systems, therefore the physiological mode relates to the physical needs of a person such as exercise, rest, fluid and electrolyte balance and general maintenance of the internal environment (Akinsanya, 1994b and Fawcett, 1990).

The physiological mode includes five basic physiological needs and four regulator processes, the physiological needs are oxygenation, nutrition, elimination, activity and rest, and protection while the regulator processes are the senses, fluid and electrolyte balance, neurological functions and endocrine functions (Fawcett, 1996 and The Roy Adaptation Model, n.d.).
The **self-concept mode** focuses on the need for psychic integrity (Crouch, 1994 and Fawcett, 1995), it encompasses the way in which a person sees oneself in society and includes the beliefs and feelings about oneself at a particular time (Akinsanya, 1994b). It includes the perception of both the physical and personal self. The physical self is viewed in terms of body image and body sensation, difficulties in this area are often expressed as a feeling of loss (Pearson et al., 1996), while the personal self is viewed in terms of self-consistency, self-ideal and the moral-ethical-spiritual self (Fawcett, 1990), difficulties in this area can be experienced as feelings of anxiety, guilt and powerlessness (Pearson et al., 1996).

The **role function mode** emphasizes the need for social integrity (Fawcett, 1990, 1995); this means the knowledge of who one is in relation to others, so that one can act (The Roy Adaptation Model, n.d.). Roles are regarded as the functioning units of society (Fawcett, 1995) therefore role function defines the sociological role played by the individual in society and what the expected behavior of the individual is to maintain that role (Akinsanya, 1994b).

Roles are classified in three:

- The primary role determines the majority of behaviors in a person's life. This role is determined by age, sex and developmental stage (Andrews, 1991 as cited in Fawcett, 1995); it is relatively consistent and pre-determined (Pearson et al. 1996).
- The secondary role is relatively permanent, however can be chosen and is linked with the stages of life (Pearson et al., 1996). They are usually achieved
positions as opposed to primary roles and need specific role performance; examples of secondary roles are parent, student or spouse (Fawcett, 1995).

- The tertiary roles are related to the other two roles, they are temporary in nature, freely chosen and relatively minor, they may include activities such as clubs or hobbies (Fawcett, 1995 and Pearson et al., 1996).

Each role contains instrumental and expressive components, instrumental components refer to the actual physical performance to master the role while the expressive component refers to the feelings a person has about a particular role (Andrews, 1991 as cited in Fawcett, 1995). Difficulties usually arise when there is a sudden change in the secondary role for example a sudden parenthood, the inability to master a role, conflicts between roles or too many roles can all cause difficulty in adaptation (Pearson et al., 1996).

The interdependence mode also emphasizes the need for social integrity, it is the fine balance between independence and dependence on others (Fawcett, 1995 and Pearson et al., 1996). Independence is shown by the ability to achieve, make decisions and initiate actions while dependence is shown by the need for affiliation with others, for their care, support and approval (Pearson et al., 1996). This mode emphasizes behaviors underlying the development and maintenance of satisfying affectional relationships with others as well as the provision and receipt of social support (Fawcett, 1990). It involves contributive, that is the giving of affection and receptive behavior that is the reception of affection (Fawcett, 1995).
Although these four modes have been discussed separately, they are in fact interrelated, because a certain behavior in one mode can affect another mode (Fawcett, 1995). In the research study to be carried out, the focus will mainly be on the three last modes since the parents being interviewed will probably be physically healthy. The three modes of self concept, role function and interdependence will be mainly affected by the birth of a premature baby. In the self concept mode things such as body image for the mother, disruption of any previous organization would alter self consistency and the parents' self ideal that they would want to live up to and could be difficult to achieve are all areas which would need adaptation. There has also been a big change in the role function mode, where now the new role of parenthood is introduced in case of a first child and if there are siblings, the role of being parents to more than one infant is introduced. In the interdependence mode the parents may have conflicting feelings about needing help and wanting to be able to care for their baby on their own. The use of the four modes in the data collection and analysis phase of the research can be very useful in giving guidance and direction to the researcher as can be seen from the examples above.

Behavioral responses within and across the four modes of adaptation can be classified as adaptive or ineffective, adaptive responses promote the integrity of the adaptive system and meet the goals of survival, growth, reproduction and mastery while ineffective responses do not meet these goals (Fawcett, 1990). These behavioral responses are thought to be influenced by environmental
stimuli. The environment is considered to be all the circumstances, conditions or changes which challenge the person as an adaptive system (Pearson et al., 1996), these factors can be either internal or external and are categorized into three groups (Fawcett, 1995).

The focal stimuli are changes or situations which immediately affect the individual and require immediate response to maintain an adaptive state, an example in this case is the birth of the premature infant or the discharge of the baby home (Akinsanya, 1994b and Tolson & McIntosh, 1996).

The contextual stimuli are all the other stimuli present in a particular situation which contribute to the effect of the focal stimuli; they are the peripheral factors that influence the situation. These factors will affect how the person can deal with the focal stimuli; an example would be living arrangements and income (Fawcett and Tulman, 1990 and Fawcett, 1990).

The residual stimuli are the characteristics, beliefs, values and attitudes of an individual which have developed from past experience but are affecting the current response. The individual may not be aware of these factors’ influence, they are part of the individual’s interaction with the environment but they are not easily analyzed as part of this interaction. When the residual stimuli’s effects become validated they become focal or contextual stimuli. An example of a
residual stimulus would be character traits (Fawcett, 1995 and Tolson and McIntosh, 1996).

These stimuli are said to merge together to form the person's adaptation level which refers to the person's ability to respond positively to a situation (Roy, 1991 as cited in Tolson and McIntosh, 1996). The individual processes the incoming stimuli through two major internal control processes called the regulator and cognator mechanisms (Tolson and McIntosh, 1996).

The **Regulator** mechanism receives input from the internal and external environment through the senses and it processes these stimuli through neural, chemical and endocrine channels. The information is channeled automatically in the appropriate way and an automatic unconscious response is produced. The response itself than becomes a stimulus which feeds back into the system for more responses (Akinsanya, 1994b and Fawcett, 1996).

The **Cognator** mechanism receives input from internal and external environmental stimuli through psychological, social, physical and physiological factors including the regulator mechanism outputs. These inputs are then processed through four cognitive/emotive channels which are:

- Perceptual/information processes which include the activities of selective attention, coding and memory.
- Learning processes which involve imitation, reinforcement and insight.
• Judgment processes which involve problem solving and decision making activities.

• Emotion processes which seek relief from anxiety and try to make affective appraisal and attachment (Fawcett, 1995).

Regulator and cognator activity is shown through coping behaviors in the four adaptive modes discussed before. Nursing goals are to promote adaptation for individuals and groups in the four adaptive modes thus contributing to health, quality of life or dying with dignity, this is done by assessing behaviors and factors that influence adaptive abilities and by intervening to expand those abilities and to enhance environmental interactions (The Roy Adaptation Model, n.d.).

Some difficulties in using the model have been noted, problems to categorize particular behaviors in each mode have been reported especially in the self-concept, role function and interdependence mode which have been noted to overlap (Fawcett, 1990, Fawcett, 1995, Hedberg Nyqvist and Sjodén, 1993 and Tolson and McIntosh, 1996). Another criticism is that maladaptation is not clearly defined and what one needs to do if the individual and the nurse hold conflicting perceptions of positive and negative adaptation (Tolson and McIntosh, 1996). The application of the model due to its multifaceted approach and due to its use of a wide range of concepts and principles derived from biology, psychology and sociology can be time consuming in practice (Akingsanya, Cox, Crouch and Fletcher, 1994). However the detailed assessment serves to ensure that
individualized care reflecting the clients' needs can be delivered (Akinsanya et al., 1994).

Some authors claim that nursing models can be too restrictive, confusing or lacking in relevance to serve as guides for nursing research (Hardy, 1982, Diers, 1984, Wells, 1987 and Frissell, 1988 as cited in Fawcett and Tulman, 1990). However other authors state that the Roy adaptation model makes a significant contribution to nursing and it offers a simple and conceptually compatible framework for use in nursing research (Fawcett, 1995) and in fact there are a number of studies based on Roy's concepts such as studies by Boumaki, (1997), Samarel, Fawcett and Tulman, (1997), Hamner (1996) and Fawcett (1990) which all show the importance of using this model for their research (as cited in Polit and Hungler, 1999).

The review of the model showed that the person is viewed as an adaptive system constantly interacting with the environment. This model in this case has been used to guide the current research study as well as to give a focus for the discussion and a basis for the findings.
Reference List:


APPENDIX NO.2

Interview Schedule (English)

Code: __________

**SWITCH ON THE RECORDER**

Background Data

Premature infant’s gestation on admission at the Neonatal Intensive Care Unit: ___________

Length of baby’s stay at the Neonatal Intensive Care Unit: ________________________

Family members living in the same household: ________________________________

1. How are you feeling now that your baby is at home? 
   -How did the discharge home of your baby affect you? 
   -Negatively and positively.
   -Any difficulties you have met.
   -What changes in your everyday life did you have to do?
   -How did these changes affect you?
   -What support did you find? (from family, friends, each other)
   -What support do you think you need?

2. What do you think about the discharge planning you received at hospital? 
   -What do you think could be added to this discharge planning?

3. Do you want to add anything about your experience in these last few weeks, after your baby’s discharge home? 
   -What do you think about the future? (the baby’s, yours)
APPENDIX NO.3

Covering Letter and Informed Consent (English)

Dear parents,

As part of a research project for my Masters Degree in Health Science, I, Diana Borg B.Sc.(Hons) Nursing, a staff nurse currently working in the Neonatal Intensive Care Unit, am going to conduct a study entitled “Parents’ experiences following discharge home of their premature infant.” The aim of the study is to explore these experiences by conducting interviews with both of you, four weeks after your baby has been discharged home, at your own home or any other place that you wish. The interviews will be tape recorded, if you do not wish so, notes will be taken instead.

I would like to invite you to participate in this study, whether you agree to participate or not is entirely your own choice and this choice will not have any affect on the care you or your baby receive. You may decide not to participate or to participate but not answer all of the questions. You also have the right to withdraw from the study at any time you wish to. Anonymity will be respected and codes will be used instead of your names, confidentiality will likewise be respected at all times and the data collected will be used solely for the purpose of the study and will be destroyed upon completion of the study. If you agree please sign below.

Signatures:

________________________________________________________________________

Date: ______________________

Thank You

Diana Borg
B.Sc. (Hons.) Nursing.
APPENDIX No. 4

Intervista (bil-Malti)

Kodici: __________

IBDA RREKORDJA

Taghrif dwar l-isfond tat-tarbija

Numru ta gimghat li kellha t-tarbija primatura meta ddahlet fin-Neonatal Intensive Care Unit: ________________

It-tul ta zmien li t-tarbija damet fin- Neonatal Intensive Care Unit: ______

Membri tal- familja li jghixu fl-istess dar: _________________________________________

1. Mill-esperjenza taghkhom kif thossukhom issa li t-tarbija tinsab id-dar?

- kif laqtatkom il-fatt li t-trabija taghkom intbaghtet lura d-dar?
- fin-negattiv u fil-pozittiv
- x' diffikultajiet li ltqajtu maghhom?)
- x'bidliet kellkhom taghmlu fil-hajja ta’ kuljum
- kif affetwawkom dawn il-bidliet?)
- x’sapport sibtu (mil-familja, hbieb u minn xulxin)
- x’ sapport tahsbu li ghandkom bzonn?

2. X’ inhi l- esperjenze taghkhom dwar kif gejtu ppreparati mill-isptar ghal meta t-tarbija tintbaghat id-dar?

-x’tahsbu li jista’ jsir iktar bhala preparazjoni f’dan il-kaz?

3. Tridu zzidu xi haga dwar l-esperjenza taghkhom ta dawn l-ahhar gimghat, wara li t-tarbija taghkom intbaghtet id-dar?

-x’ tahsbu fuq il- futur? (ghalikhom u ghat tarbijja)
APPENDIX NO.5

Ittra ghall-kunsens tal-genituri

Ghezieg genituri,


Jekk taqblu iffirimaw hawn taht, jekk joghgbokom.

Firem

Data

Grazzi

Diana Borg
B.Sc(Hons)Nursing
TO WHOM IT MAY CONCERN

RE: Masters Degree in Health Science
APPLICATION: Ms. Diana Cassar

I am writing to confirm that I have no reservations and, indeed, would strongly support Ms. Diana Cassar’s proposal for a research study as part of her Masters Degree in health Science.

Yours sincerely,

[Signature]

DR. S. ATTARD MONTALTO
Chairman Paediatrics