

“The Greek hospital and community nurse’s role of offering support, counselling skills and nursing rehabilitation to parents of children with chronic medical, surgical or genetic conditions or disabilities.”

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For the degree of Doctor of Philosophy**

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DECLARATION

This thesis has been submitted for the fulfillment of the requirements for the award of Doctor of Philosophy, School of Nursing and Midwifery Studies, University of Wales College of Medicine, University of Wales, Cardiff.

The study was planned and completed by myself, under the supervision provided by Professor Phillip Burnard. All ethical considerations were taken to ensure the rights of the participants.

The study was designed specifically for the award for which it has been submitted and has not been, and will not be, used for any other academic qualification. It is submitted to the university to be lodged and utilized in accordance with the rules and regulations of the University of Wales, Cardiff.

Signed.....*telera*.....*Michaelopoulou*.....

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I would like to take this opportunity to acknowledge the people who contributed to this study. I thank the parents and the nurses who took the time to participate in this study. I wish to express my sincere appreciation to my supervisor, Professor P. Burnard, whose inspiration, advice and suggestions were invaluable to the production of this thesis. I would also like to thank my parents, especially my father for his support and guidance.

ABSTRACT

Children with altered body images due to chronic illnesses, surgery, genetic diseases or disabilities are living longer (Newacheck *et al.*, 1998) which requires nurses to undertake their basic nursing role of providing psychological support through offering information, counselling and nursing rehabilitation (Johnson, 2000; Maguire and Parkes, 1998). The parents of these children face a drastic change in their lifestyle which requires them to adapt by using personal, family and community resources, according to Hentinen and Kyngas (1998).

The aim of this study was to explore the perceptions of Greek nurses and parents of children with chronic health problems (CHP) in relation to the nurse's role of offering psychological support. This study used a data and methodological triangulation approach which included two levels of persons, parents and nurses, and a combination of qualitative and quantitative paradigms. A survey was given to 103 parents and 83 community or hospital nurses, from these samples 30 parents and 30 nurses were chosen to be interviewed. King's Conceptual Framework of Goal Attainment (CFGA) guided the study and provided a framework in which to present the findings.

The main findings from the descriptive analysis, chi-square and Fisher's exact tests, along with the qualitative findings, concluded that many nurses and parents both felt that nurses were not well enough informed, many nurses had offered information but parents refused to accept it and that many parents and nurses were unaware of the nurse's role in nursing rehabilitation. A disagreement was found between the samples as to whether or not it was the nurse's role to evaluate the adaptation of the child and his parents, an important part of nursing rehabilitation according to Gibbons *et al.* (1995). Additional findings were that a few parents had the fear of surgery for their child, there was great disagreement concerning the importance of whether or not these children should attend public school and that many health conditions could have been prevented. Although religion had not been included in the questionnaire, during the qualitative portion of the study the parents emphasised the importance of their Greek Orthodox religion as a source of strength. Comparisons of the

perceptions of both sample groups provided information which may assist in developing future approaches in nursing practice, nursing research and nursing education.

TABLE OF CONTENTS

Declaration.....	a
Acknowledgements.....	b
Abstract.....	c

Chapter I. Introduction

1.1. Introduction.....	1
1.2. Aim and Reasons for Choosing the Subject.....	2
1.3. King's Systems Framework and Theory of Goal Attainment.....	5

Chapter II. Literature Review

2.1. Introduction.....	6
2.2. Phenomenology.....	10
2.3. Individual System-The Person.....	13
2.3.1. Perception-An Individual's Representation of Reality.....	13
2.3.2. Self.....	16
2.3.3. Body Image.....	17
2.3.4. Alterations in body image.....	19
2.3.5. Growth and Development	20
2.3.5.1. <i>Ways of Classifying Disabilities</i>	21
2.3.5.2. <i>Definitions and classifications of chronic health conditions</i>	22
2.3.6. Nursing rehabilitation.....	24
2.3.7. Time and space.....	26
2.4. Interpersonal System.....	28
2.4.1. The Role of the Family within the Interpersonal System	28
2.4.2. Interaction	29
2.4.3. Communication	31
2.4.4. Counselling.....	32
2.4.5. Transaction.....	35
2.4.6. Stress	35

2.4.6.1. Time-bound Theories of Grief.....	39
2.4.6.2. Chronic Sorrow.....	40
2.5. Social System.....	44
2.5.1. Stigma and Chronic Conditions.....	44
2.5.2. Education.....	46
2.5.3. Health System	47
2.5.3.1. <i>Organisation</i>	47
2.5.3.2. <i>Power</i>	47
2.5.3.3. <i>Authority</i>	48
2.5.3.4. <i>Decision Making</i>	49
2.5.3.5. <i>Role</i>	49
2.5.3.6. <i>Nursing role and medical model</i>	49
2.5.4. <i>Community and Social Interaction</i>	54
2.6. Conclusion.....	58
2.7. Summary.....	59

Chapter III. Method

3.1. Aim of the Study.....	60
3.2. Research Questions.....	60
3.3. Research Design.....	62
3.3.1. <i>Phenomenology</i>	68
3.4. Settings of the Qualitative and the Quantitative Studies.....	71
3.5. Samples in the Qualitative and Quantitative Studies.....	73
3.5.1. <i>Parent Sample</i>	73
3.5.2. <i>Nurse Sample</i>	73
3.6. Inclusion Criteria.....	73
3.7. Ethical Considerations.....	74
Part I. The Qualitative Study	
3.8. Data Collection	76
3.9. Instrument.....	77
3.10. Content Validity.....	78

3.11. Pilot Study.....	78
3.12. Data Analysis.....	78
3.13. Validity and Reliability of the Qualitative Study.....	80
3.14. Presentation of Findings.....	82
3.15. Limitations of the Qualitative Study.....	84

Part II. Quantitative Study

3.16. Procedure of the quantitative study.....	85
3.17. Research Tool of the Quantitative Study	85
3.18. Rational for questionnaire development	86
3.19. The Questionnaire.....	89
3.20. Validity and Reliability.....	90
3.21. Pilot Study.....	91
3.22. Data Analysis of Quantitative Study	92
3.23. Limitations of Quantitative Study.....	92
3.24. Summary.....	92

Chapter IV. Findings of the Qualitative Study

4.1. Introduction.....	94
4.1.1. <i>Description of the sample of 30 parents that were interviewed.....</i>	94
4.2. “...Planning a journey to Italy...but landing in Holland!...”	95
4.3. “I pray that he is not on crutches...”	97
4.4. “We will always make sure Anne is in fashion...”	98
4.5. “We treat her as normal...”	99
4.6. Analysis of the findings from the parents’ interviews.....	100
Theme 1. “We have had no support...”	100
Theme 2. “No information was provided...”	101
Theme 3. “Upon hearing the diagnosis we felt ‘great sorrow’.”	102
Theme 4. “Our faith helps us....”	104
Theme 5. “We have many fears for the future...”	108
Theme 6. “...it could have been prevented!...”	110
Theme 7. “Rehabilitation is most important...”	111

4.7. Analysis of findings from the nurses' interviews.....	114
4.7.1. <i>Introduction</i>	114
4.7.2. <i>Description of the sample of 30 nurses that were interviewed</i>	114
<i>Nurses' Theme 1 "We don't discuss the diagnosis...we don't even change dressings!"</i>	115
<i>Nurses' Theme 2 "Families don't want our advice."</i>	119
<i>Nurses' Theme 3 "Parents don't mourn...their child didn't die."</i>	122
<i>Nurses' Theme 4 "The parents don't register their children...social stigma"</i> ...122	
<i>Nurses' Theme 5 "many parents fear that they will die before their child"</i>	123
<i>Nurses' Theme 6 "Rehabilitation is done by therapists..."</i>	123
4.8. Conclusions of Qualitative Findings.....	124
4.9. Summary	127

Chapter V. Findings of the Quantitative Study

5.1. Description of the Parents' Sample.....	128
5.2. Description of the Nurses' Sample	128
5.3. King's Individual System.....	129
5.3.1. Self and Body Image	129
5.3.2. Growth and Development Including Nursing Rehabilitation.....	133
5.3.3. Time and Space	136
5.4. King's Interpersonal System	139
5.4.1. Role	139
5.4.2. Communication: The role of offering information.....	142
5.4.3. Stress	144
5.5. King's Social System	148
5.5.1. Community - Social Stigma.....	148
5.5.2. Parent-Support Groups.....	150
5.6. Comparison of the parents' and the nurses' perceptions using Chi-square and Fisher's Exact Test.....	153
5.7. King's Individual System.....	154
5.7.1. <i>Self and Body Image - Statistically Significant Findings</i>	154

5.7.2. <i>Self and Body Image - Non-Statistically Significant Findings</i>	157
5.7.3. <i>Growth and Development - Non-Statistically Significant Findings</i>	158
5.8. King's Interpersonal System.....	160
5.8.1. <i>Nurse's role - Statistically Significant Findings</i>	160
5.8.2. <i>Nurse's Role- Perception of Support - Non-Statistically Significant Findings</i>	163
5.8.3. <i>Communication Non-Statistically Significant Finding</i>	164
5.9. King's Social System.....	166
5.9.1. <i>Social System- Statistically Significant Findings</i>	166
5.9.2. <i>Parent Support Groups-Statistically Significant Findings</i>	167
5.9.3. <i>Community- Social Stigma Non-Statistically Significant Findings</i>	168
5.10. Summary	169

Chapter VI. Discussion

6.1. Introduction.....	170
6.2. King's Personal System.....	172
6.2.1. Self.....	172
6.2.2. Self-esteem.....	174
6.2.3. Nurse's role in nursing rehabilitation.....	175
6.2.4. Perceptions of Nurse's Role in Offering Information.....	177
6.2.5. Parents' Fears.....	181
6.3. King's Interpersonal System.....	185
6.3.1. Nurses' Role of Offering Counselling and Psychological Support.....	185
6.3.2. Stress-Chronic Sorrow.....	190
6.4. King's Social System.....	192
6.4.1. Community-Social Stigma.....	192
6.4.2 Public schools- Special schools.....	192
6.4.3. Parent-Support Groups.....	194
6.5. Conclusion.....	195
6.6. Summary.....	196

Chapter VII. Conclusions, Recommendation and Summary

7.1. Conclusions of the Qualitative Portion of the Study.....197

7.2. Conclusions of the Quantitative portion of the study199

7.3. Recommendations201

 7.3.1. *Recommendations for future nursing research*.....201

 7.3.2. *Recommendations for nursing practice*.....202

 7.3.3. *Recommendations for nursing education*.....203

7.4. Summary204

References.....i-xx

Appendix I. Parents’ and Nurses’ Questionnaire

Appendix II. Description of the sample of 30 parents that were interviewed

Appendix III. Description of the sample of 30 nurses that were interviewed

Appendix IV. Description of the parent sample who participated in the quantitative portion of the study (N=103)

Appendix V. Description of nurses’ sample who participated in the quantitative portion of the study (N=83)

Appendix VI. Parents’ Responses to the Questionnaire

Appendix VII. Nurses’ Responses to the Questionnaire

Appendix VIII. Parents’ and nurses’ responses (Items: 1, 2, 4, 5, 13, 15, 16, 17, 18, 20, 33, 34)

Appendix IX. Chi-square and Fisher’s Exact Test Findings: Comparison of Parents’ and Nurses’ Responses

Appendix X. Decision trail and Audit Trail of one Theme

List of Figures

Figure 1. Parents' Responses - Children with CHP often felt inadequate and lacked self-esteem.....	130
Figure 2. Nurses' Responses - Children with CHP often felt inadequate and lacked self-esteem (Item 26)	130
Figure 3. Parents' Responses - Children with CHP cared for themselves (Item 8)	131
Figure 4. Nurses' Responses - Children with CHP cared for themselves (Item 8)	131
Figure 5. Parents' Responses - Parents were the sole caregivers (Item 3)	132
Figure 6. Nurses' Responses - Parents were the sole caregivers (Item 3)	132
Figure 7. Parents' Responses - Nursing care and rehabilitation should focus more on psychological rather than physical improvements (Item 36)	133
Figure 8. Nurses' Responses - Nursing care and rehabilitation should focus more on psychological rather than physical improvements (Item 36)	133
Figure 9. Parents' Responses - Nursing rehabilitation's goals should address each child's personal needs (Item 35)	134
Figure 10. Nurses' Responses - Nursing rehabilitation should be based on personal needs (Item 35)	134
Figure 11. Parents' Responses - It was the nurses' role to evaluate how well the child and family were adapting (Item 23)	135
Figure 12. Nurses' Responses - It was the nurse's role to evaluate how well the child and his family are adjusting. (Item 23)	135
Figure 13. Parents' Responses - Nurses encouraged parents to plan for a productive future (Item 11)	136
Figure 14. Nurses' Responses - Nurses encouraged parents to plan for a productive future (Item 11)	136
Figure 15. Parents' Responses - Nurses should encourage parents to plan for their child's future and encourage their independence (Item 27)	137

Figure 16. Nurses' Responses - Nurses should encourage parents to plan for their child's future and encourage their independence (Item 27)	137
Figure 17. Parents' Responses - Nurses needed to provide parents with up to date information for possible future health problems (Item 28)	138
Figure 18. Nurses' Responses - Nurses needed to provide parents with up to date information for possible future health problems (Item 28)	138
Figure 19. Parents' Responses - Nurses had offered parents support and encouragement (Item 9).....	139
Figure 20. Nurses' Responses -Nurses had offered parents support and encouragement.....	139
Figure 21. Parents' Responses - Nurses had suggested treatments when others failed (Item 10)	140
Figure 22. Nurses' Responses - Nurses had suggested treatments when others failed (Item 10)	140
Figure 23. Parents' Responses - Nurses felt uncomfortable when discussing a child's diagnosis (Item 21)	141
Figure 24. Nurses' Responses - Nurses felt uncomfortable when discussing a child's diagnosis (Item 21)	141
Figure 25. Parents' Responses - Physicians were the only qualified personnel to offer information concerning the child's condition (Item 22)	142
Figure 26. Nurses' Responses - Physicians were the only qualified personnel to offer information concerning the child's condition (Item 22).....	142
Figure 27. Parents' Responses - Nurses should answer the parent's questions since they were well informed (Item 24)	143
Figure 28. Nurses' Responses - Nurses should answer the parent's questions since they were well informed (Item 24)	143
Figure 29. Parents' Responses - The child's condition could have been prevented (Item 12)	144
Figure 30. Nurses' Responses - The child's condition could have been prevented (Item 12)	144

Figure 31. Parents' Responses - Parents often suffered from sorrow and depression since they had "lost" their perfect child (Item 30)145

Figure 32. Nurses' Responses - Parents often felt periods of sorrow and depression having lost of their 'perfect' child (Item 30)145

Figure 33. Parents' Responses - Parents often feel joy and happiness from their child (Item 31)146

Figure 34. Nurses' responses - Parents often feel joy and happiness from their child146

Figure 35. Parents' Responses - Parents were not grieving since their child was alive147

Figure 36. Nurses' Responses - Parents were not grieving since their child was alive (Item 25)147

Figure 37. Parents' Responses - Children with CHP were accepted by society (Item 7)148

Figure 38. Nurses' Responses - Children with CHP were accepted by society (Item 7).....148

Figure 39. Parents' Responses - Children with CHP should go only to special schools and not public schools (Item 14)149

Figure 40. Nurses' Responses - Children with CHP should go only to special schools and not public schools (Item 14)149

Figure 41. Parents' Responses - Parent-support groups help parents cope with their children's CHP (Item 6)150

Figure 42. Nurses' Responses - Parent-support groups helped parents cope with their children's CHP (Item 6)150

Figure 43. Parents' Responses - Parents feel better after talking with other parents about their situation (Item 19)151

Figure 44. Nurses' Responses - Parents feel better after talking with other parents about their situation (Item 19)151

Figure 45. Items 3, 8, 26.....154

Figures 46. Items 23, 11, 28.....155

Figure 47. Items 1, 2, 4.....157

Figure 48. Items 5, 36, 35, 34.....	158
Figure 49. Items 9, 13, 10, 22.....	160
Figure 50. Items 20, 31, 25, 32.....	161
Figure 51. Items 27, 33.....	162
Figure 52. Items 21, 29.....	163
Figure 53. Items 16, 18, 24, 30.....	164
Figure 54. Items 7, 14, 12.....	166
Figure 55. Items 19, 6	167
Figure 56. Items 17, 15.....	168

Chapter I. Introduction

1.1 Introduction

According to Creasia and Parker (1991), even before the birth of their child, parents begin to develop an idea of what their child will be like. When the reality of the child does not match the parents' ideal image, such as when an ill or disabled child is born, significant adjustments must be made. These adjustments are also required when a healthy child becomes chronically ill or disabled. These parents need to use coping techniques to change or handle the situation, or to change or handle their emotional response to their situation. Hentinen and Kyngas (1998) identified three kinds of coping resources, personal, family and community. They pointed out that parents needed to activate one or more of these resources as a coping response. The personal resource was the belief that the individual was capable of handling the situation. Family resources were the social, psychological, interpersonal and material attributes that were offered by the family members. Community resources were the social, psychological, interpersonal and material attributes that people outside the family such as individuals or groups, could offer parents. These resources included religious organisations, as well as friendships and support groups.

Chronic health problems (CHP), as defined by Perrin *et al.* (1993), were disabilities or illnesses which were expected to last for an extended period of time and as Meleski (2002) points out these children require special medical attention and more care than normal children need. Included in this extra care could be extensive hospitalization or in-home services. Among these conditions are arthritis, asthma, cystic fibrosis, diabetes, spina bifida, seizure disorders, cancer, neuromuscular disease, acquired immunodeficiency syndrome, cerebral palsy, and genetic diseases, such as haemophilia and Down syndrome. According to the severity of the CHP, there was an impact on the child's physical, intellectual, psychological and social functioning. This impact occurred because of persistent symptoms, limitations in activity and mobility, and extensive medical treatments that interfered with school and family activities (Perrin *et al.*, 1993).

According to Perrin *et al.* (1993), researchers and health care professionals recognised CHP as lifelong illnesses requiring complicated daily management regimens in order to maintain

control, achieve growth and development, prevent complications and promote and sustain optimal functioning for the child. Meleski (2002) suggested that usually full responsibility for the day-to-day care of the child depended on the parents. They were expected to achieve an appropriate standard of competence in caring for their child that ensured the provision of safe, effective and managed care of their child.

According to Nolan and Nolan (1999), chronic illnesses and disabilities represented a significant health challenge and there was great concern about the rehabilitative needs of chronically ill and disabled people. Sapountzi-Krepia *et al.* (2001A) maintained that nursing has a potential role, which until now was mostly unrealised. They suggested that since these parents need to regain control of their situation, facilitating the flow of information should be one of the nurse's highest priorities. The nurse's role could be used to implement three major nursing actions which include facilitating, supporting and advocating (Chen *et al.*, 2002; Sapountzi-Krepia *et al.*, 2001A). Support should be offered to these parents through the use of counselling skills. Sapountzi-Krepia *et al.* (2001A) conducted a Greek study and believed that nurses, as advocates, could speak out on the parents' behalf or encourage them to do so. Nurses could also offer other resources which were available depending on the child's diagnosis, such as parent-support groups that parents could attend.

1.2. Aim and Reasons for Choosing the Subject

This study was undertaken to explore the perceptions of Greek nurses and parents of children with CHP in relation to the nurse's role of offering support, counselling skills and nursing rehabilitation. This topic was chosen since there was lack of previous work in this field. The need for this special group of children to be included in a research study was demonstrated in an article by an English reporter, Midgeley (1997). She wrote that reporters from the United Kingdom (UK) visited Greek institutions and filmed a documentary. They claimed that they found mentally and physically disabled children who never left their beds or saw daylight and were tied to their beds in rooms containing up to 30 cots. She wrote that due to the social stigma, these children were kept out of sight.

It was of interest to explore whether nurses were aware of the psychological aspects of care needed by parents while caring for a child with a CHP. Another important aspect of this study was to explore the parents' and the nurses' perceptions in relations to the nurses fulfilling this role. Through this study the information gained could be useful in planning appropriate support services to improve these parents' adaptation to caring for and rehabilitating their children. In Greece, encouraged by the extra attention they received by hosting the Para Olympic Games in 2004, many groups for the disabled became very vocal and attempted to improve old services and create new ones.

As Maguire and Parkes (1998) explained, these children have a life-long challenge that needs to be monitored properly by the nursing personnel involved. In the UK it is the role of the hospital and community nurse to offer support to these children and their parents for their future losses that will occur and to reassure them that their feelings of fear and grief are normal and expected. Nurses are expected to offer psychological support by allowing the parents to express their fears without being judged and they are obligated to answer their questions and to provide appropriate literature. The information and booklets are offered without the parents' requests since nurses are more aware of what information each parent needs and what is available. Nurses introduce the parents to support groups and monitor any problems that occur and refer them to specialists as needed. These children are not treated for a few days, cured and released but, unfortunately, their problem goes home with them.

Included in this study was an overview of the concepts identified in the literature, such as body image and altered body image along with the importance of supportive communication, counselling skills and nursing rehabilitation which are needed to be offered by nurses in order to provide holistic care for these paediatric patients and their parents throughout all phases of their lives.

Casarett *et al.* (2001) pointed out that the grieving process was experienced when coping with CHP. Thus, one of the points of interest in this study was to discuss if parents and nurses recognised the grieving process. For this reason a description of the two schools of

thought concerning grief counselling was included: the “time-bound grieving model” and the “chronic sorrow model”.

Sapountzi-Krepia *et al.* (2001) suggested that nurses’ communication and counselling skills were needed to assist the child and his parents in adjusting to his altered body image. Nursing rehabilitation was included, in this study, since it was an important part of preparing these children for their future. According to the Association of Rehabilitation Nurses (2004), and even though Henderson described it back in 1965, nursing rehabilitation is established as a new field of nursing. It differs from the usual rehabilitation fields in that the nurses have an active role in coordinating the other members of the rehabilitation team, and supervise the goal setting for each child. These goals were not set according to the illness but according to the ability of each individual child. Since the abilities in CHP differed from other health problems, a different approach was needed. For example, when a child had an acute health problem the goal could be “*will be able to feed himself in 3 days*”, while in a chronic illness there cannot always be improvement since the condition often worsens, so it is important to set the goal based on the present abilities of the child. For this reason it might be sufficient to just maintain his abilities, for example “*will continue to feed himself for the next six months*”.

In order to explore this subject, both data and methodological triangulation approaches were used. The data triangulation approach involved two levels of persons, the parents and the nurses. The methodological triangulation approach involved the use of the qualitative and quantitative paradigms. The findings of the qualitative study, which consisted of interviewing 30 parents and 30 nurses, were presented along with the themes.

For the quantitative part of the study, a survey was given to 103 parents and 83 nurses and a descriptive analysis was presented along with the results of the chi-square and Fisher’s exact tests that were carried out to statistically compare the responses between parents and nurses.

1.3. King's Systems Framework and Theory of Goal Attainment

Creasia and Parker (1991), Dempsey and Dempsey (1996) and Nieswiadomy (1987) recommended that a research study should follow a conceptual framework in order to develop a better research design and to assist in guiding the study. This allows the results to fit into the existing body of nursing knowledge. Thus, after reviewing the conceptual frameworks available, King's Systems Framework and Theory of Goal Attainment was chosen (King, 1981). According to King (1981), role incongruence leads to break downs in the nurse-patient relationship which prevents them from setting and obtaining goals together. These goals are very important since they lead to better coping and adapting for the parents, which can assist them in caring for their children.

King's Conceptual Framework identified concepts important to nurse-patient interactions that needed to be addressed and in this study an attempt was made to classify the literature accordingly. Since it was possible to classify studies under several concepts, the most appropriate choices were made. In this way, a better understanding and a more holistic picture of the subject being studied was provided.

The literature relevant to the topic will be presented in the following chapter.

Chapter II. Literature Review

2.1. Introduction

A systematic literature review was carried out to obtain all the relevant, current literature on the topics of interest to this study. Several search engines on the World Wide Web were used such as “Yahoo” and “Google”. Databases, such as OVID, CINAHL, MEDLINE, and the British Nursing Index were included. The key words used in the search were: “paediatric nursing”, “community nursing”, “psychological support”, “counselling skills”, “communication skills”, “body image”, “body image alteration”, “patient’s perceptions”, “statistics of disabled children in Greece”, “attitudes toward children”, “chronic illnesses”, “nursing rehabilitation”, “bereavement”, “chronic sorrow”, “diabetes”, “Down syndrome”, “haemophilia”, “autism” and “disabled children in Greece”, along with “genetic diseases” and “chronic disabilities”.

Many nursing frameworks and theories were studied as possible choices for this research study since Dempsey and Dempsey (1996) suggest the use of a framework to provide a logical structure to guide the development of a study and to help link the findings to the nursing body of knowledge. Among those suggested was Roy’s Adaptation Model, but it was rejected along with the other frameworks since they were not consistent with the subject being studied (Marriner-Tomey, 1989).

This research inquiry identified Imogene King’s Interacting Systems Framework and Theory of Goal Attainment (King, 1981) as its conceptual framework. King, a well-known nursing theorist, founded her theory in 1964, but it was 1971 before the entire conceptual framework was presented.

This conceptual framework was chosen to guide this study since it identified concepts of interest to the subject. King identified the nursing process as reciprocal because goal identification exists between nurses and patients and was described as the concept of transaction (reciprocal goal identification). King wrote that her framework had four concepts centred around man as an open system which were identified as social systems, interpersonal relationships, perceptions and health (Creasia and Parker, 1991).

King defined perception as

“each human being’s representation of reality” (1981, p.61).

A definition of the meaning of “perception” was included here for a better understanding of this study. Perception, as defined by King (1981), is developed and related to one’s self concept, inherited characteristics, and is influenced by one’s level of education, social and economical status. Based on these characteristics, perception gives meaning to life’s experiences, defines one’s impression of reality and determines one’s behaviour.

King (1981) claimed that each individual used his past experiences to assign meaning to new experiences by an active process of human transaction. Assumptions were identified, in other words, they were statements that were taken for granted or were considered true without scientific testing (Burns and Grove, 1997). As an assumption, King (1981) identified humans as perceiving beings that were capable as open systems to interact with their environment. She described humans as social, rational, controlling and action-oriented individuals. The environment was identified as an open system with internal and external stressors acting on the individual as he interacts with his environment. Health was described as one’s ability to continue to adjust to the internal and external stressors of the environment. Illness was described as when there was no adjustment to these stressors creating an imbalance in biological structure, psychological status or social relationships.

King (1981) described “*nursing*” as action, reaction and interaction processes which occur between the nurse and the patient that included communication to set goals and to discover ways to meet these goals. The first concepts were those that were related to the nurse-patient relationship: the Personal System- the individual, the Interpersonal System- two or more interacting individuals, and the Social System which included communities and societies. The second set of concepts dealt with goal attainment: interaction, perception, communication, transaction, role, stress, growth and development, time and space.

“*Interaction*” was the verbal and non-verbal behaviours directed toward goal achievement. “*Perception*” was the unique way in which each individual believed something was in reality and “*communication*” involved the transferring of information

among individuals. "*Transaction*" was the way an individual interacted with his environment and was witnessed by behaviours that were observable. "*Role*" included the various behaviours carried out according to an individual's position within a social system. "*Stress*" was defined as a dynamic condition in which energy and information were exchanged between a person and the environment in an attempt to maintain and control stressors. "*Growth and development*" were defined as continuous changes occurring to each individual at cellular and behavioural levels that help him progress towards maturity. "*Time*" was described as the time between one occurrence and another, while "*space*" was referred to as an individual's actions in which he expressed his boundaries to personal space, the area in which the patient and the nurse interact. King was positive about the individual's right to receive knowledge about himself, the right to make informed decisions that concern his life, health, community service and the right to accept or reject health care if he felt it was unfit.

King's seven hypotheses from her Goal Attainment Theory were of importance to this study's objectives. As described by King (1981) they were:

1. Perceptual agreement between nurse and patients lead to goals determined by both parties.
2. Communication is important to goal setting and satisfaction.
3. Satisfaction increases goal attainment for both parties.
4. Stress and anxiety are reduced when goals are met.
5. Patients learn more and can cope better when goals are met.
6. Role incongruence is a negative action because it limits transactions between the nurse and the patient.
7. An agreement with role expectance and role performance has a positive effect because it increases transactions between nurse and patient interactions.

King identified that stress and anxiety would be reduced if there was no role conflict, this would lead to improved transactions and goal setting, which was described in the literature as an important part of nursing rehabilitation (Gibbons, 1997).

Literature relevant to this topic is presented according to the components of King's Conceptual Framework. This framework provided an adequate guide and emphasised the concepts related to the topic of this study. King (1981) identified the importance of the

nurse's ability to interact with people within their environment by their ability to function through the use of roles. The individual, the client who throughout this study was referred to as the "parent", and the nurse need to interact in such a way as to attain mutually agreed upon goals. Through the process of action, reaction, and interaction both nurse and parent communicate, set goals, and determine ways to achieve these goals.

King (1981) suggested in her Theory of Goal Attainment that the goal of nursing was to assist individuals to be able to function in their roles by maintaining their health which applied to this study. There were two main concepts of this theory: the first involved the nurse-patient relationship and the second was concerned with goal attainment. In this way, parents learned to cope which led to adapting to their child's condition. By adapting they were able to live with the child's condition, comply with carrying out the child's treatment, and at the same time meet their own needs and the needs of their other children (Hentinen and Kyngas, 1998).

Each system's concepts, as identified above, were described and reviewed here according to the literature included in this study. The concept of "person" in this study was the child with the altered body image due to his chronic condition, the parent, and the nurse. The term "chronic health problem" (CHP) was used instead of "chronic illness or disability", the nurse was referred to as "she" and the child as "he". The concepts included under the Individual System were "perceptions", "self", "body image", "growth and development", "time" along with "space". "Growth and development" included nursing rehabilitation since it was associated throughout the child's life of developing to his full extent, physically and emotionally. The "time" concept included the thoughts and concerns for the future along with the transition periods that occurred throughout the lifetime of the child affecting the parents' adjustments. The "space" concept included the child's home, hospital or health centre, or anywhere that nurse-parent interactions occurred.

The second system, the Interpersonal System of two or three people, discussed families and their interactions with nurses. "Communication" included the use of counselling skills needed for goal attainment to be successful. Following the concepts of "transaction and stress", the literature concerning grieving, including "time-bound theory" and "chronic sorrow" were presented.

The third system, the Social System which included the education and health care systems, encompassed the concepts of “organisation”, “power”, “authority”, “decision making” and “role” as they applied to the child, the parents, or the nurse. “Community and social interactions”, including “social stigma”, concluded the literature review.

2.2. Phenomenology

Phenomenology is both a philosophy and a research method and a brief history of the philosophy will be discussed here. The phenomenological movement, as a philosophy, began in the early 20th century, and consisted of three phases, preparatory, German and French (Streubert and Carpenter, 1999). The preparatory phase involved two important people, Franz Brentano (1838-1917) and his student Carl Stump (1848-1936). The German phase included philosopher Edmund Husserl (1859-1938) and his student, Martin Heidegger (1889-1976). Heidegger had Nazi involvement and is criticized because he did nothing to help Husserl, a German Jew, in his retirement years. The German phase of phenomenology ended with the Nazi years and Husserl’s papers were moved to France after his death. The key persons in the French phase were Gabriel Marcel (1889-1973) and Maurice Merleau-Ponty (1908-1961) (Cohen *et al.*,2000).

Crotty (1996) declares that presently there are two types of phenomenology, the first is Husserl’s phenomenology and the second is a North American type developed by sociologists and psychology writers. Husserl’s eidetic phenomenology was influential since the Duquesne school of phenomenology was based on his philosophy. The researchers there included Giorgi (1985), Colaizzi, Fischer, and Van Kaam (1966). These are the researchers most often mentioned in nursing research (Cohen *et al.*,2000).

There is also a Dutch phenomenology of the Utrecht School, van Manen has described Dutch phenomenology and its use in empirical research and it is labelled hermeneutic phenomenology. Phenomenology has become more popular among nursing researchers since it is, in Husserlian terms, a way to study “a lived experience” (Wimpenny and Gass, 2000).

Husserl’s philosophy developed since he saw the inadequacies of the theories of knowledge at that time. He objected to the positivism doctrine that it was necessary to

separate the external world from the internal world by implementing methods and procedures that controlled and standardised human subjectivity. Husserl argued that the positivists' belief that there was a world of facts, irrespective of what people thought of them, was incorrect. He believed that before the world becomes an object that we know, it is an experience that we have lived. Husserl suggested that it is necessary to uncover the process by which human consciousness gives meaning to the lived experience, which he named "phenomenology", its Greek root meaning "appearance" (Porter, 1998).

Thus, Husserl, and his student, Heidegger, wrote about the need to describe and interpret complex phenomena (Krasner, 2001). Husserl, a Jew living in Germany in the 1930s, was aware of the dangers in categorising human beings as objects. While in exile from Nazi Germany, he gave a lecture on accepting the human spirit as a necessary and important part of each individual. It is suggested that this philosophical approach might appeal to those interested in offering holistic care.

In Husserl's approach to the study of human consciousness there are features to any lived experience that are common to all persons who have lived the experience, these are called "universal essences" or "eidetic structures". Husserl defined the importance of phenomenological reduction, or eidetic reduction or "bracketing" to determine the universal essences. Bracketing was considered as an effort to set aside the researcher's own assumptions of the reality being studied. It was also a way to reduce the influences of the stories from the previous informants in order to fully hear the story of the present informant (Sarter, 1988). In other words, it appears to be an attempt to set aside prejudices and to prevent the researcher from projecting his thoughts into the interviews. Husserlian phenomenologists believe that the self and the world are mutually shaping, and by bracketing one can see the world in a new way.

However, Heidegger turned away from Husserl's study of "essences" toward a study of "being". Heidegger and Merleau-Ponty considered phenomenological reduction or "bracketing" as impossible since they felt humans can not detach themselves from their feelings and beliefs. Their hermeneutic method was carried out by interpreting the participant's experience in the light of socio-historical influences (Wimpenny and Gass, 2000; Polit and Hungler, 1991). A new point of interest to this argument concerning bracketing was introduced by LeVasseur (2003) when she suggested that the researcher

has already bracketed his prior understanding when he became curious enough to undertake a study since he was admitting that he did not know everything about that subject.

However, all phenomenologists do agree that reality is subjective and depends on the unique experiences of the individual, and so reality exists as each individual sees it (Burns and Grove, 1997).

In nursing research there are two main phenomenological approaches used, Husserl's eidetic or descriptive approach and Heidegger's hermeneutic or interpretive approach. Eidetic phenomenology deals with describing the lived experience while hermeneutics have to do with interpreting the meaning of the lived experience (Porter, 1998).

Eidetic or descriptive phenomenology consists of three steps: intuiting, analysing and describing (Spiegelberg, 1984). In intuiting, the researcher becomes the tool in the interview which is the main method of data collection. In phenomenological research the relationship between the researcher and the participants become reflective.

Phenomenology is assisted by the researcher through the use of an interview. Interviews are not to explain, to predict or generate theory, they are for the sole purpose of understanding the participants' vivid descriptions of their lived experiences. The researcher listens to the participant's description during the interview, without criticism, evaluation or opinion.

Analysis is done by the researcher repeatedly reviewing the data and identifying the essence or themes of the experience based on the data. The third step is phenomenological describing. This includes all critical elements or themes to be described in such a way that the researcher is able to communicate the meaning of the lived experience. Sorrell and Redmond (1995) point out that listening is thought to be as important as the narrative since the researcher is the tool. This places a great responsibility upon the researcher to properly tell the narrative in such a way as to obtain all the richness and context of the experience.

Porter (1998) declared her fascination over the last ten years with a book, "*Ideas*", originally written in 1913 by Husserl concerning his philosophy of phenomenology. A

part of the inspiration she received was Husserl's advice on how to describe the lived experience in common speech, Porter felt this added to her interactions with the elderly women participating in her study, along with the fact that she was a nurse and interested in obtaining a true interaction, without worrying if it was an appropriate psychological method. Porter claimed Husserl offered her the freedom to proceed as a nurse to reassure the participants who then reacted positively. However, the use of phenomenology in nursing has been criticized by Crotty (1996) as having a lack of relationship between the original philosophy and the new philosophy and May (1991) called attention to "method slurring". These qualities create a lack of rigour and, thus, qualitative findings are not as respected as much among some scientists (Wimpenny and Gass, 2000).

Krasner (2001) explained that the "phenomenologists" had not envisioned research as the "logical positivists" but believed in a more humanitarian approach to building a body of knowledge. Mathematical formulas were not seen as possible in depicting the human phenomena. Krasner (2001), after studying Heideggerian hermeneutic phenomenology, supported the importance of qualitative research and she mentioned that stories of the lived experiences teach and speak to the soul and are more touching than any raw data could be. Her finishing comment is quoted here since this researcher finds it to be appropriate to this study.

"Stories illuminate meaning, meaning stimulates interpretation and interpretation can change outcomes" (Krasner, 2001, p.72.)

2.3. Individual System-The Person

2.3.1. Perception-An Individual's Representation of Reality

Noyes' (1999) qualitative study of 10 mothers' perceptions of their children being ill in an intensive care unit focused on the psychosocial needs of these mothers. She claimed to have used a grounded theory approach in her study to develop a theory as the interviews progressed. She emphasised to the participants that she was a nurse but not working in the intensive care unit, which was a positive action so as to reassure the mothers that their participation would not influence their children's care. However, a limitation of this study was that the mothers were not asked to verify the analysis since the children had been discharged. Thus, it would appear that this was not a grounded theory approach because repeated interviews were not carried out which constitute a vital element to a

grounded theory approach (Burns and Groves, 1997). This study described the mothers' shock and crisis since their normal lives were disrupted which resulted in role changes from being mothers of normal children to the role of being mothers of very sick children. Each mother had a child with a different diagnosis, which was a generic approach since it included different illnesses and each mother had a different experience. The results were that nurses were described as very supportive and informative, parents were allowed to see their child 24 hours a day and eventually they were allowed to help care for their child, which the mothers perceived as making coping easier. Noyes (1999) recommended family-centred nursing and suggested the need for more nursing research on the coping mechanisms of parents.

Chen *et al.* (2002) studied parents of children with acute and chronic illnesses and offered the same recommendations. They encouraged professionals to meet the psychological needs of parents whose children had an acute or chronic illness by offering information and resources that were available. Their case controlled study included 32 parents of children with Duchenne Muscular Dystrophy (DMD) and a control group of 30 parents whose children had only a fever. This study took place at a University Hospital in southern Taiwan. However, it was interesting that the parents of the children with DMD sought help from doctors rather than other parents or relatives. The control subjects, those whose children had a fever, used resources including doctors and relatives, although both groups avoided approaching nurses for information.

The fever group used emotional expression, self-blame, information-seeking, and threat minimization as ways of coping, while the DMD group used wish-fulfilling fantasy. It is important to remember that DMD is a genetic disease affecting only young boys and these boys have a life-expectancy of ten to twelve years. This study demonstrated that parents of the fever group used doctors, not nurses, as a major source of support suggesting that nurses needed to challenge their current roles since they had the potential of having a positive impact by offering information and support to parents. They maintained that nurses should understand that cultural meanings need to be given to the child's illness and that parents need to undertake their care-giving roles by carrying out their customary routines. Also, nurses should provide information which empowers parents, resulting in parents' improved self-esteem and competence (Chen *et al.*, 2002).

Garwick *et al.* (1998) studied parents' perceptions of what they found to be “*helpful versus unhelpful types*” of social support offered while caring for their preadolescent children with chronic conditions. This was a qualitative study of a volunteer sample of parents of 124 children with a variety of CHP. Quantitative data was collected through the use of questionnaires in order to assess and compare support sources. Interviews were conducted at base line and one year later. Content analysis was used to define unsupportive behaviour. This study reported that family members were the main source of support while health care professionals were important for providing helpful information. The parents reported 388 incidents of unsupportive behaviour from health care professionals and family members. Conclusions were that support from the family was stable over the year but there were problems with the health care system that needed to be addressed. It appeared that the parents had not expected nurses' support and, therefore, they did not feel disappointed when most nurses did not offer support or information. However, most of these parents wanted only support, not information, from family members.

In another study, parents felt better just by the perception that nurses were there to support them. Kurst and Schulman (1988), as cited in Garwick *et al.* (1998), found that parents of children with leukaemia functioned better when they “perceived” that support was available, even when it was not. The perception that they were not alone enabled them to adapt better to their situation. In Garwick *et al.* (1998), it was suggested that lack of support had a negative effect on families' adjustments to CHP. They emphasised that a person's social network was needed to provide emotional, tangible and informational support. However, Dunken-Schetter (1984), as cited by Garwick *et al.* (1998), found a difference between emotional support and advice. The families believed emotional support was helpful from all sources, but advice was only respected from health care workers and not family members. There appeared to be different perceptions depending on the source of the support.

The weaknesses of Garwick *et al.*'s. (1998) study were that it consisted of a volunteer sample and it was not made up of typical families. The volunteer sample may have introduced bias by the inclusion of well-functioning families since families in distress probably would not have volunteered to participate in a long-term study. The sample was made up of two-parent, middle class, white families, which were not the typical families

(Newacheck *et al.*, 1998). A low participant rate and the homogeneous nature of the sample limited the generalizability of the findings to other populations (Garwick *et al.*'s, 1998).

Hatton *et al.* (1995) conducted a qualitative study that offered an interesting insight into parents' perceptions of caring for an infant or toddler with diabetes. The parents reported feelings similar to the five stages of the time-bound theory of grieving of Kubler-Ross (1970). The parents grieved for the loss of their child's health, and in addition, for the loss of their own lifestyle. Some parents had to change job patterns in order to be able to care for their children with diabetes. Other parents reported the difficulty in obtaining time alone as a couple since caretakers would not care for a sick child while others could not be trusted with the responsibility of the management of the disease. Some parents even mentioned the "loss of joy" from their lives. CHP that cause grieving were demonstrated in this study which illustrated the importance of qualitative research since it provided a more vivid description of the parents' pain and anguish. However, other authors, such as Kearney and Griffin (2001), described the "joy" that the families expressed in their study, which will be discussed later under "stress adaptation".

2.3.2. Self

Price (1990) described body image, self-esteem, role performance and role identity as the four aspects of a person's self-concept. Each aspect developed from birth and reflected the changes that take place during the lifetime.

A study concerning "self" was conducted by Yan *et al.* (1999), it was a descriptive study in order to evaluate the self-concept of hospitalized Chinese children with various chronic illnesses. A purposeful sample of 122 children with nephritic syndrome, leukaemia and congenital heart disease participated. The children's records, demographic forms and the Piers-Harris Self-concept Scale were used to collect the data. The results showed that the majority of the hospitalized school-age children had an average level of self-concept. However, the results were in disagreement with Noll *et al.* (1999) as their study of children with cancer reported better self-concepts than the case control group.

Yan *et al.*'s (1999) explanation for their results suggested that these children may have been in "denial" and that they had answered as they wanted their life to be and not as it

actually was. These researchers suggested that their results could be implemented into nursing practice by nurses encouraging positive self-concept development of each child based on his academic achievement, age, sex, illness and duration of illness. They recommended that nurses should arrange for these children to interact more with their teachers and classmates in order to encourage positive self-concept development. Their research was very thoroughly carried out and the results were clearly presented in tables.

In a study conducted by Camfield *et al.* (2001), 114 children with epilepsy were included in order to establish their level of self-esteem. Their conclusions were that the more severe the epilepsy was, the lower the children's self-esteem and the more emotional problems they encountered. These children had parents who found them less acceptable due to their severe condition. In agreement with this were Carson and Heiber (2001) who reported that a supportive adult could prevent children from having low self-esteem by enabling the children to see themselves as competent. They suggested that nurses needed to send positive messages to the child and to encourage caregivers to do the same. Nurses should assess and communicate the child's self-image and his level of being able to care for himself to the other health care team members.

Burt (1995) discussed the key effects of radical treatment on body image and the role of nurses as counsellors. She defined body image alterations as the loss to the "self" which results in a loss of social identity and role. An important point that she made was that adolescents, who were already sensitive about their "self" and sexuality, needed nurses to offer them the opportunity to discuss sexual issues. However, Burt (1995) argued that nurses usually felt uncomfortable talking about sexual subjects since their educators had not prepared them for discussing such topics. She suggested that not all nurses were needed to be sex therapists, but they should be aware of the effect that altered body image can have on sexuality in order to prevent these children from developing feelings of low self-esteem.

2.3.3. Body Image

Stuart and Sundeen (1987) defined body image as a part of the self-concept. The self-concept is developed as a result of each person's unique experiences within himself, with other people, and with the realities of the world.

Price (1998) identified normal body image as possessed by each individual, the three main components of normal body image were body reality, body presentation and body ideal. Body reality was how one's body was, such as tall or short, the physical creation of the body. Body presentation was how one dresses and poses his body. Body ideal was how one thinks he should look and this idea changes and is influenced by many factors (Bycroft, 1994; Jamieson, 1996). Price's (1990) model described normal body image as when the three components were held in balance by social support and coping strategies. This model suggested that people with few social supports were more likely to develop psychological problems. They were less successful in adjusting to changes in normal body image. For this reason, a discussion of social support systems and coping strategies will be presented.

Culture and society influenced the importance of having a positive body image, which was seen by the emphasis on "youth and beauty" by our society (Lawler, 1991). When a person's body image did not meet the norms set by society, there was a conflict between mind and body. This conflict caused a risk to one's physical and mental health, as well as to his body image health. Many authors agreed that people have difficulties adapting to changes to their body image (Deusen, 1993; Jamieson, 1996; Salter, 1988, Chen *et al.*, 2002). According to Creasia and Parker (1991), in situations of paediatric body image alterations, nurses were needed, along with other health care professionals, to support and assess the child's self image and level of independence. It was essential for nurses to help children and families cope with chronic, debilitating, progressive diseases. Families needed support since they suffered from feelings of powerlessness and hopelessness. As their child experienced loss of various functions, the parents grieved over these occurrences.

Lugton (1997) maintained that nurses' support for patients' relatives was also important since the illness of one family member caused stress to others. Offering information was most requested by the patients and the family members taking part in her study.

McMahon *et al.* (2001) conducted a study of siblings of children who had severe traumatic head injuries. The convenient sample of eight siblings, 2 to 14 years old, all described their lives as changed forever but refused to comment on whether their lives became better or worse.

2.3.4. Alterations in body image

Altered body image was classified by Price (1990) as any change to body image that was not part of normal growth and development. These alterations could occur from an internal or an external environment, or a combination of both. Internal alterations were such problems as congenital defects, genetic disorders, degenerative diseases, psychiatric and hormonal disorders. Examples were mental retardation, diabetes, arthritis, blindness and deafness.

External alterations could be due to trauma, cancer, radiation, surgery, medical treatment or infections. However, although Beer (1995) agreed with this classification, the researcher included other alterations like renal and cardiac diseases. Beer included these diseases since the body no longer functioned at the optimum level and the child was physically limited. A person's body image was altered when there was a change in the appearance or function of a body part. Amputation or facial disfigurements were obvious alterations affecting body image perception. Colostomy and ileostomy, although not apparent when a child was dressed and active, altered the appearance and function of the body. The significance of body alteration varied among individuals and among cultures (Groce and Zola, 1993; Price, 1990).

An altered body image had a definite impact on children and their parents when the child's ability to function as a normal human being deteriorated. There was a loss of self-esteem and self-worth. The nurse played an important role when caring for a patient whose body image was about to be changed, such as before surgery, or after it had been changed (Brennan, 1994, Gibson, 2001; Kelly, 1994; Price, 1998). The nurse may be the first role model a child and his family encountered following an alteration to body image (Maksud and Anderson, 1995). It should be taken into account when providing holistic care that any type of body image alteration may affect the child's social, physiological and spiritual factors (Borwell, 1997).

Norris *et al.* (1998) conducted a cross-sectional, qualitative study focusing on specific body alterations at specific times. They reported that there was a potential influence on self-esteem as a result of body image alteration either due to appearance or dysfunction. They conducted an interesting study by interviewing 28 participants at 3, 6, 12 and 18 month intervals following physical alterations due to a variety of causes. They attempted

to formulate a grounded theory in re-imagining forming a framework for developing and organising knowledge concerning body image alterations.

Purposeful sampling was used to ensure a variety of ages and types of body alterations. The study included 32 participants in the beginning but 4 of them dropped out before completion. The various alterations were rapid weight loss or gain, paralysis of a limb or amputation, colostomies, surgery, trauma and cardiac transplantation. The review and analysis of the data carried out grounded theory development.

Rigor was evaluated as Sandelowski (1986) suggested by auditability, credibility, fittingness and confirmability, which were deemed more appropriate in evaluating qualitative studies. Themes of grief were common in Norris *et al.*'s. (1998) study, in those grieving beyond a year it was considered due to complications of depression. This work offered insight into a subject that requires more research to test the correlation between factors concerning altered body image adjustments. However, in disagreement with these ideas of being signs of depression were Dashiff (1993) and Hainsworth *et al.* (1994) whose studies claimed that grieving for over a year was not considered depression, but "chronic sorrow".

2.3.5. Growth and Development

The present survival rate of children with serious chronic conditions is rather high, for example, 90% of those born with a disability can survive to age 20 (Newacheck *et al.*, 1998). Nursing literature was available concerning asthma and diabetes mellitus, while some other diseases were ignored.

When discussing the concepts of growth and development, chronic conditions were included since they were abnormal aspects of growth and development. Nursing rehabilitation was included since it was the way of maintaining independence as long as possible throughout these periods of growth and development which lead to maturity as described by King (1981).

A qualitative study was carried out by Stuijbergen and Rogers (1997) to identify a model of health-promotion behaviour and the quality of life of persons with chronic disabling conditions including multiple sclerosis. These authors pointed out that persons with

slowly degenerating diseases such as arthritis, lupus or multiple sclerosis were not often hospitalised and, therefore, they did not have structured rehabilitation. These individuals needed health promotion knowledge and rehabilitation to improve their quality of life. A main goal of rehabilitation, along with health promotion, was to encourage self-care and independence in order to improve the quality of life. In order to create a model, the researchers sought to obtain the perceptions of the lived experience of individuals with a chronic disability. Results of a study by Wineman (1990) pointed out that support groups, along with perceived support of family and friends, resulted in better psychosocial adjustments.

2.3.5.1. Ways of Classifying Disabilities

A number of conceptual approaches were used to classify and characterise children with chronic conditions. These methods had been used for over 40 years to identify target populations for public programmes serving children with chronic conditions. Three of the approaches used were: “condition lists”, “functional impairments”, and “disability” (Newacheck *et al.*, 1998). According to “condition lists” the children were divided into lists according to their chronic condition. “Functional impairments” were assessed to determine if they had impairment in basic functions such as hearing and if the child could carry out daily activities such as bathing, eating and dressing. “Disability” was used to classify children if they were limited in socially defined roles such as school or play.

Newacheck *et al.* (1998) conducted a study by reviewing the results of the National Health Interview Survey on Disability (NHIS-D) and estimated the number of children in the United States (US) with existing health care needs. The estimates were based on 30,032 completed interviews with children under 18 years old. The response rate was 87%, usually the mothers answered, but children over 16-years-old could answer for themselves. This study discovered two groups: one group received a high level of services while the other group needed services but was not receiving them. This second group was not receiving services due to several reasons such as access barriers, lack of knowledge on the part of the parents, along with other factors. It was found that children in this group experienced more developmental delays, learning disabilities, vision and hearing impairments, and other types of functional limitations and disabilities (Newacheck *et al.*, 2000).

They concluded that in 1994, 18% of the children under 18, or 12.6 million children, had a chronic physical, developmental, behavioural, or emotional condition that required health related services not needed by children in general. Their study suggested that school-aged children were twice as likely as toddlers, and boys were one third more likely than girls to be characterized as having special needs. African-Americans were more likely, while Hispanic and other minorities were least likely to be characterized as having special needs. Children from low-income families were about one third more likely to have health needs, whereas the higher educated parents had a lower incidence of children with special needs. Children in single-parent families were 40% more likely to have health care needs. Eighteen per cent of these children and their parents reported dissatisfaction with their care and 13% claimed that they had unmet health care needs (Newacheck *et al.*, 1998).

2.3.5.2. Definitions and classifications of chronic health conditions

Chronic health conditions varied in their nature and severity and their requirements of medical services. Programmes developed in order to care for these children required a great deal of health carers and funds. Perrin *et al.* (1993) emphasised that although there were differences in each health condition there were also common factors involved. Some common factors were the need for a variety of community and health professional services, the challenge to maintaining a positive self-image and emotional development, an increased financial burden, and a greater strain on the family's relationship and social life. Until recently chronic conditions were considered to be those expected to be lengthy, such as diabetes, cerebral palsy and deafness. Researchers and those creating health programmes found dissatisfaction in this way of classifying by individual health conditions.

However, empirical studies confirmed that there were common factors so that each condition did not need to be studied individually, which was costly and time-consuming (Perrin *et al.*, 1993). Children with uncommon illnesses had problems with the condition-specific approach since they were excluded from recreational activities, school programmes and mutual help-groups. These activities were regionally organized since locally there were not enough children with a particular health problem to form a group.

Perrin *et al.* (1993) also pointed out that the generic grouping of all chronic conditions should be done, however, they then continued to argue that there are many problems with organizing the conditions this way. They felt the terms “illness” and “disabilities” should not be used since these children were not ill. They suggested the term “chronic condition” to be more accurate and favoured. They supported the generic approach as the way to assist those individuals involved in health care issues to organise their efforts more effectively (Epping-Jordan *et al.*, 2004; Plante *et al.*, 1991).

In 1990, a US Supreme Court decision demonstrated the importance of a broad generic definition of childhood disability. In order for a disabled child to receive benefits, the child needed to be diagnosed with a specific condition which placed the importance on the condition, not the child. As a result, children whose conditions could not be specifically diagnosed could not receive benefits. To correct this situation, instead of defining disabilities according to their diagnosis, the disabilities were considered according to the functional ability of the child. This decision recognized the ability of the child to function in five categories: cognition, communication, motor functions, social abilities, and patterns of interaction, regardless of what the illness of the child might be (Perrin *et al.*, 1993).

However, Usner *et al.* (1998) claimed this was not beneficial to specific diseases such as genetic diseases which required specialized research. An example of a genetic disease was haemophilia. Haemophilia was classified according to its severity and often produced severe musculoskeletal complications which caused visible and functional body image changes. These complications were acute periods of joint pain, loss of range of motion, chronic joint disease and disability. The two types of treatment were “on-demand” versus “prophylaxis”. Research generically carried out does not identify treatment modalities to reduce these musculoskeletal complications and the high cost of treatment. Other specific research interest of children with haemophilia was whether their frequent absences from school interfered with their academic and social development (Shapiro *et al.*, 2001). So it appeared that not all children with special diseases would benefit from generic classification of illnesses when it came to research.

2.3.6. Nursing rehabilitation

A child's growth and development was jeopardized when a major interruption of normal life experiences occurred. This occurred with all developmental disabilities, traumatic injuries, and acute and chronic illnesses. According to the Association of Rehabilitation Nurses (2004), rehabilitation nursing was a specialty that improved the quality of life for children with CHP and their families. These nurses worked with the other health care professionals toward a continuum of nursing care from diagnosis to productive adulthood. The goal was for the child to function at his full potential and to become a contributing member of society. This included the physical, emotional, social, cultural, educational, developmental, and spiritual dimensions. Each child was considered unique (Association of Rehabilitation Nurses, 2004).

Rehabilitation nurses were required to be empathetic and to have excellent listening and counselling skills. These skills were needed in order to think of inventive ways to assist these children in reaching their goals. It was understood that the child and his family's goals were important and not what the medical and nursing staff considered important. When there was a disagreement as to the goals, the staff needed to discuss this with the family but the family needed to have the final decision unless, of course it was damaging to the health of the child (Gibbons *et al.*, 1995).

The nurse's role in nursing rehabilitation was suggested by Henderson (1980). There were two ways of looking at the nurse's role in rehabilitation, one way was that rehabilitation was a part of the routine nursing care since the nurse was consistent in carrying out all care with the interest of improving the status of the patient and encouraging positive outcomes (Henderson *et al.*, 1995). However, the second way was to consider nursing rehabilitation as a separate field which required special training (Association of Rehabilitation Nurses, 2004).

Nolan and Nolan (1999) reported that they studied the nursing curricula in the UK to identify if nurses were being educated for their potentially important role of caring for chronically ill and disabled people. They found that nurses were not being taught enough courses and information concerning chronic illnesses and disabilities. Nurses had a greater need for this information since more and more people with chronic illnesses lived with, rather than died from their diseases (Nolan and Nolan, 1999). According to

Gibbons *et al.* (1995), the concept of rehabilitation needed to be re-evaluated. They discovered that rehabilitation focused on improving physical functioning. Those individuals with permanent disabilities or progressive degenerative conditions found such an aim as being counterproductive. Placing such importance on the physical improvement created tensions for the future since these individuals' conditions usually became worse, not better.

There were many problems concerning current nursing rehabilitation practice, one was that professionals saw it as a time-limited intervention (Gibbons *et al.*, 1995). However, Avramazi (2004) argued that some Greek disabled or chronically ill persons and their carers did not share this concept and they felt that rehabilitation needed to address their on-going needs. Insufficient attention was paid to their emotional and psychological needs, along with the work and vocational aspects of their care. In agreement with this are Betz (2003) and Hammel (2003) who suggest that a person with severe disability has a right to supportive recourses and to the same level of respect, dignity, and quality of life as any other member of society. According to Avramazi, insufficient attention was given to specific areas of concern, such as sexuality and issues concerning gender, culture, ethnicity and the needs of family's carers.

Vardakastanis and Chatzipetrou (2004) suggested that insufficient attention was given to the attitudes and environmental barriers, preventing the full integration of people with CHP into society. Rehabilitation focused too much on physical problems while often ignoring psychological adjustment issues. The literature identified the above deficits in current rehabilitation practices and it was pointed out that nurses could play a role in decreasing these deficits. Gibbons *et al.* (1995) suggested that nurses needed to understand the parents' feelings in order to set and meet attainable goals, not just the traditional goals. According to King (1981), it was important to try and understand the person's perspective of a life-altering situation. Sapountzi-Krepia *et al.* (2001) argued that to achieve this, changes were needed in basic nursing education in Greece. Greater attention needed to be given to the areas that nurses could legitimately claim as an element of their expertise and to identify nursing rehabilitation as one of their duties. They suggested that this would benefit children with CHP and their families while at the same time it could add a new dimension to nursing.

2.3.7. Time and space

King (1981) included the concept of “time” as the period in which events occur and the concept of “space” as the place where interactions take place. The role of the nurse changed and was unique to a given setting or space. In discussing time, it would be appropriate to include the transition periods of time which occurred as the with CHP grew and developed, along with the parents’ fears for the future (Meleski, 2002).

Meleski (2002) defined the five transition periods as: diagnosis, during a parent’s absence, increased symptoms, developmental milestones, and changes in the course of the illness. At the time of diagnosis, parents were aware that something was wrong but the actual diagnosis caused the destruction of the family’s balance or equilibrium. Clements *et al.* (1990) found that 70% of the parents claimed that learning their child’s diagnosis was the most difficult period.

Meleski (2002) continues that during a parent’s absence, family reorganisation was needed to replace the missing family member. For example, in divorce the parent remaining with the child must undertake more roles and responsibilities. At times when the child had increased symptoms, tasks were considered stressors for parents that included administering medication, carrying out treatments and planning treatments. The attitudes of the parents influenced whether or not these were considered stressful procedures. At developmental milestones, when a child had not attained age-appropriate milestones it caused chronic sorrow. The parents were forced to change their expectations whenever the delays became apparent.

Changes in the course of the illness caused a transition period, also when the outcome of the illness was uncertain or if the child was hospitalised. Farley (1990) studied the emotional responses of parents of disabled, premature, and chronically ill children. She found that the parents suffered from feelings of helplessness, frustration, depression, anger and irritability when their child experienced the stressor events of illness, surgery, attending day-care and being surpassed developmentally by a younger child.

Although these premature children in her study were healthy, the parents frequently expressed a fear that they felt that their child would die during future surgery. One father, whose daughter had surgery twice, commented that it was like reliving a nightmare (Farley, 1990). In agreement were Villarreal and Johnson (1995) who reported the

importance of the nurse's role in assessing the intellectual, psychosocial and physical status of children and their families when the developmentally disabled child needed surgery. Communication skills were important in order to deliver family-centred nursing care.

Meleski (2002) emphasised that each family went through transition periods and their view of the particular condition along with the amount of care the child needed were important factors as to how well they adjusted. Regardless of the child's diagnosis, all families became more upset during periods of transition. However, it was felt that families understanding that chronic sorrow and the use of denial were normal reactions did not suffer as much during these periods. For this reason, nurses needed to be able to recognise the five transition periods and to be aware of the stressors and the emotions involved in each transition period.

To build supportive relationships and to have successful transactions, King (1981) suggested that it depended on whether or not the nurses were properly trained. Nurses were required to recognise the family's attitudes toward the illness or disability, the care required and the burden involved which influenced the level of stress the family felt. Nurses must realise that the parents' emotional reactions were normal and often served the purpose of protecting them. The emotional reactions of denial and chronic sorrow were most often seen according to Hentinen and Kyngas (1998).

However, Clubb (1991) described a different set of transition periods for parents of children with autism and Down syndrome. These critical periods were when normal children usually learned to walk at 12-15 months old, when they usually started to talk at 24-36 months old, also when they usually entered school, at the usual onset of puberty and on the child's twenty-first birthday. When these particular milestones were not met, the parents were reminded that their child was not normal.

All of these transition periods were highly stressful, they disrupted normal routines and they demanded adjustments from parents and siblings. The family used coping strategies more effectively if they were less stressed during these periods. Clubb (1991) concluded that when nurses had prepared the family to assess the child's health situation and to take action in making decisions on a regular basis, the family felt more secure and comfortable

in performing their skills. In this way they coped better during transition periods since their stress levels were not as elevated as the families that found it difficult to cope on a regular basis. Meleski (2002) pointed out that these difficult periods occurred to all families of chronically ill children but nurses helped shorten the duration of them and lessened the degree of disruption that occurred. Nurses predicted some of these periods and assisted the family to prepare for them before they began. When the nurse recognised that such a period was about to happen, the parents were psychologically prepared with more information and choices so as to support them when the period actually arrived (Bailey *et al.*, 1992).

Johnson (2000) identified the primary goal of the nurse which was to educate the parents by offering them the knowledge and skills they needed to adjust to their situation. The parents often needed help in many areas, such as obtaining additional support, modifying their expectations of their child's abilities, planning the least restrictive environment in school and in taking care of medical treatments.

Various approaches had been used in conducting research studies of families with children with chronic illnesses, such as a disease-specific approach versus a generic approach. A limitation of the disease-specific approach was that the population was usually limited and, thus, the findings could not be generalized. The generic approach was based on the idea that parents faced similar problems regardless of their child's diagnosis. This approach helped families concentrate on coping strategies, provided common adaptation goals for parents and supplied an assessment tool for nurses to evaluate the transition periods (Meleski, 2002).

2.4. Interpersonal System

King (1981) defined the interpersonal system as the unity of two or three people referring to these units as dyads or triads.

2.4.1. The Role of the Family within the Interpersonal System

Tseng and Hsu (1991) recognised the family as a critical social unit which carried the cultural traditions and beliefs from one generation to another. Included were the beliefs and practices concerning health, illness and chronic conditions (Tseng and Hsu, 1991).

Health care professionals should be ethnically and culturally competent in recognizing, respecting and engaging in ethnic diversity in order to obtain a mutually desired outcome. It was important to realize that traditions have given families a sense of stability and support. Greek families drew comfort from these traditions and found guidance and ways of coping with their daily problems (Tripp-Reimer and Sorofman, 1998).

According to Tripp-Reimer and Sorofman (1998) the Greek society consisted of the “extended family,” which included not only the couple, but also the children, the older relatives, the grandparents, uncles and aunts and even a distant cousin was included if he was considered an expert in the problem at hand. These family members played a part in making the decisions, assisted in offering care and emotional support. As Groce and Zola (1993) pointed out, some societies had a structured hierarchy. There was a line drawn between members of society according to family connections, education and wealth, as seen within the Greek society (Tripp-Reimer and Sorofman, 1998).

2.4.2. Interaction

Physical, psychological, social and economic variables played a part in the ability of the family to adapt. Meleski (2002) proposed several types of adaptation that parents used at transition phases. They were support, assigning meaning to the illness, managing the condition, role reorganisation and normalisation. Nursing interventions needed to be negotiated depending on the type of family adaptation and the particular situation (Coyne, 1997B; Deatrick *et al.*, 1999; Gravelle, 1997).

Johnson (2000) mentioned “support” as the most beneficial in helping families adapt, with the support of relatives, friends, health professionals, support groups and religious sources. Nursing interactions during diagnosis included assessing the family members’ abilities to express their concerns and to meet them. Nurses should be able to evaluate existing support systems within and outside the family. At other transition times, nurses gave parents feedback, they acted as a link between school and family and they identified parent support groups.

Garwick *et al.* (1998) identified the social support system as a network that provided emotional, support and information. Most parents existed within several support systems such as family, community and health care services. The three social support network

clusters were the family, the health care service provider and the community. The family had five sources of support: spouse/partner, children, parents/in-laws, siblings and other relatives. The health care service consisted of doctors, nurses, teachers, hospital chaplains, social workers, therapists and mental health professionals. The community was made up of friends, neighbours, co-workers, ministers or priests, church members and illness-related support groups.

Parents, who were usually unhappy but relieved to know their child's diagnosis, needed in addition, clear and truthful information. Any plans for the child's future needed to be based on current and reliable information. Meleski (2002) insisted that nursing interventions should be directed towards helping the family identify what the illness meant to them since after diagnosis the parents were responsible for the care of their child. Families mentioned various strategies that were helpful such as "*can do*" attitudes, "*other parents do it*", and "*one day at a time*". Some families mentioned that they tried to appreciate the good times of their family's life. It was reported that families having a good relationship with the health care team managed their child's illness better, these relationships facilitated in offering the support and education of the skills they needed. Nursing interventions provided included offering educational material, providing demonstrations of equipment along with information concerning up-to-date treatments.

Role reorganisation was often necessary during the transition periods. In this way some of the responsibilities of the child's care and the home chores were redistributed in order to cover all the needs of the family. Nursing interventions were aimed at assisting families with role reorganisation and included the child assuming the role of his own care under the supervision of a parent, as in the case of a diabetic child. Normalization involved acknowledging the child's condition and its possibility to threaten their life style. The parents considered their life normal and interacted with others in the same way. There was a constant struggle to try to act as if everything was normal, when it was not. Parents did not perceive their child's illness as normal but they perceived their management of the illness and their family life as normal. They presented their family to others as a typical family (Meleski, 2002).

2.4.3. Communication

The nurse's non-verbal reactions to body alterations helped determine how well the family accepted the various changes that occurred to their child (Jamieson, 1996). Johnson (2000) introduced the theory of parental straddling. In this study, parents were described as living in the past and present and trying to treat their child as "normal", while dealing with their own and their child's feelings. It was important that nurses comprehended how difficult it was for these parents to fulfil these roles and tasks. Nurses allowed parents to express their fears and feelings in a non-judgemental environment. Nurses prepared parents in anticipation of the transition phases as discussed previously. Thus, it was important for nurses to understand their vital role since they had a significant impact on patients (Black-Monsen, 1999; Johnson, 2000; Meleski, 2002).

Fitzpatrick (1999) reported that even uneducated and socio-economically disadvantaged patients wanted to learn about their condition, but often they did not know what to ask. Educating the patients and including them in making important decisions and in discussing long-term treatment plans minimized recovery time, as reported by Huygen *et al.* (2000). They maintained that it was important to assign this chore to a specific member of the healthcare team, such as the nurse. In this way, chances of a patient being neglected was reduced, which in turn offered the reassurance of the delivery of individualised patient care.

The basic principles of counselling were for one to take the time to listen, offer support and reassurance, to recognise and focus on feelings and to treat each individual as unique (Heron, 1990). Eakes *et al.* (1998), emphasised the importance of the role of "empathetic presence" of someone. Empathy was the ability to perceive and reason, and to communicate understanding of the other person's feelings. This was an important part of a helping relationship (Baillie, 1996). However, Reynolds and Scott (2000) discussed nurses' lack of empathy after conducting an extensive and enlightening literature review dealing with the importance of empathy. They claimed that concerns about body image, sexuality or death were human responses that patients felt they wanted to be included in the nurse-patient relationship, but they were not usually included. These feelings and issues were expressed by Amvrazi (2003) concerning disabled people in Greece. Daniel (2002) in her qualitative study, mentioned similar complaints about issues of sexuality. It was discovered that the responses of the participants to their diagnosis depended upon the

information that they had received prior to their diagnosis. Those who had a family member who had not done well with the disease accepted the diagnosis very poorly. One participant who knew someone managing very well with the disease was not as alarmed by the diagnosis.

Patient satisfaction was identified by Eriksen (1995) as the degree to which the patient's expectations were met. Patients expressed satisfaction when nurses showed empathy, communicated with them, provided them with information and appeared to have professional knowledge and skills according to Redmond and Sorrell (1999).

Reynolds and Scott (2000) reported that primarily actual health problems were treated and discussed with doctors, while an empathetic nurse was needed to discuss other more personal subjects. However, nurses must be prepared and properly informed for such a nurse-patient interaction to be successful.

2.4.4. Counselling

Nurses could be classified under using counselling skills as part of their everyday role without being professional "counsellors" (Heron, 1990). Hedlund and Jeffrey (1993) suggested that the key to counselling was to listen without judgement, without moralizing and without offering advice. It was important to understand the person's personal theory of why they do things in order for the nurse to be able to help them. Other recommendations were to ask open questions, to reflect, and to try to empathise with people. The outcome of counselling should be action, in order to assist these parents in identifying and solving their problems while basic counselling skills of listening and attending were useful. An empathetic and warm nurse could encourage parents and their families to talk about their fears and worries. Counselling is a very personal experience and, thus, the client must feel very comfortable with the nurse in order to obtain a therapeutic relationship (Rogers, 1961). Heron (1990) made an important observation that no matter what nurses offer in terms of counselling skills it must be remembered that the client must be willing and able to change in a positive way.

Heron (1990) described his Six Category Intervention Analysis that has been used in training nurse teachers and practitioners in using communication skills. Heron (1990) divided all therapeutic interventions into six types, the 'prescriptive', the 'informative',

the 'confronting', the 'cathartic', the 'catalytic' and the 'supportive'. He described the first three as the 'authoritative' and the last three as 'facilitative' counselling interventions. It is not necessary to use all six types but it is more important to choose the right type for the right experience.

Balen *et al.* (2001) suggested that researchers have begun to include children's own opinions on matters that concern them. It was thought that this would empower children and lead to data important to children's needs. However, each study should employ the proper methodology based on an assessment of each need. Many studies were discussed, pointing out the difficulties involved, such as the importance of the child having the proper linguistic skills needed to understand the question and to respond appropriately when interviews were conducted. Closed questions resulted in the child guessing or by simply answering affirmatively to questions with yes-no answers.

The employment of fun activities often assisted a child in better expressing himself. They emphasised the need for researchers to build a rapport with the children. For this reason, two meetings were included, one was to meet the child and to explain the research study and the second meeting was to carry out the research. The first meeting included presenting enough information to allow the children to make a fully informed decision concerning their participation. Another issue was gaining access to these children, which was often very difficult. They suggested that the efforts were worth it since the children were worthy of study in their own right.

Listening included hearing what the other person was saying along with the non-verbal communication, the linguistic aspects and the choice of words that they used. Hedlund and Jeffrey (1993) discussed the causes of interruption to communication which could be caused by lack of privacy, constant interruptions, the counsellor's own problems or the lack of attention. Attending and listening were skills for the nurse to develop for nursing patients and families but also for interpersonal relationships and for improving self-awareness.

Barrat (1989) studied the self-perceived role of 16 community psychiatric nurses. These nurses believed that counselling assisted individuals in coping with their feelings and

problems, and that community nurses had an important role by offering basic counselling skills to patients and their families.

Carson and Heiber (2001) suggested that self-help groups offered another form of counselling in most communities for parents of children with various chronic health problems such as diabetes, asthma, cancer, congenital heart disease, cystic fibrosis, Down syndrome, muscular dystrophy and phenylketonuria. Since the members of these groups had to cope with similar situations, these groups offered a special kind of support. New parents that joined the group received encouragement and support from older members who had adapted to caring for their own child with a body alteration. A new member was linked with a partner, another more experienced parent that offered support and information as needed.

Group work was also encouraged by Almeida (1995) as a positive intervention for families whose children had diabetes. These groups offered support and assisted the family in adapting to a new lifestyle. These parents offered each other emotional support so that they became a cohesive group, which allowed them the freedom to express even negative feelings. This was a cathartic process, which had a positive effect on the family's overall coping.

She went on to describe that the group leader was considered a valuable source of support and knowledge since education concerning adaptive and maladaptive behaviour on the part of the child was critical. Families with adolescents were informed concerning this phase of their child's life, when the child was seeking autonomy through rebellion. A typical experience for an adolescent was to be self absorbed and confused since peer pressure was very strong during this period of the child's life. The parents were prepared to face this challenge with the added stress and worry of the illness. The family unit had to avoid conflict but at the same time the parents needed to avoid being overprotective in order to allow the child to be more autonomous. Since the parents were worried about the illness, this was a very difficult task. However, there were positive results when the child became more independent with the management of his condition.

2.4.5. Transaction

Concerning transactions, it often appeared that Greek families wanted to be pictured in a most positive way to outsiders and, thus, Coclami and Bor (1993) reported that they were not always truthful concerning compliance to the health care professionals. Their feelings of anxiety or depression were hidden from outsiders, yet anger was permitted to be expressed, according to (Tripp-Reimer and Sorofman, 1998).

2.4.6. Stress

Many studies concerning families of children with disabilities described negative parental reactions such as shock, denial, grief, anger, depression and chronic sorrow (Canam, 1993; Clements *et al.*, 1990; Garwick *et al.*, 1998; Johnson, 2000). However, it was also important to look at the more positive aspects of family coping, strength and growth during the raising of a child with CHP. It appeared that some disabilities required more adjustments than others, depending on the amount of physical care the child needed. In a study by Leonard *et al.* (1993), it was found that one-third of the sample of caretakers needed more help in managing the care as their children became older and more severely impaired. These mothers were in the worst mental and physical health and it was felt that they had received less emotional support from family and friends.

Seidman and Kleine (1995) developed a theory of Transformed Parenting based on their interviews with parents of children with developmental delays or mental retardation. Their theory consisted of two parts, the introduction process and the ongoing process. The introduction process was when the parents received and responded to their child's diagnosis. The second part, the ongoing performance process allowed the parents to deal with the reality of interpreting their child's problem, adjusting to the family's changes and accepting the emotional support offered by others.

In another study, Canam (1993) discussed the adaptive tasks undertaken by parents with chronically ill children. This study focused on the parents since they had the major responsibility for the care of the child as well as for the adaptation of other family members. The first task parents had to accomplish was that of accepting the child's diagnosis. Upon diagnosis, the parents were faced with feelings of shock and denial. Denial as an initial emotional response was beneficial since it gave the parents the opportunity to slowly adapt to the threat of the illness.

However, a realistic view of the situation promoted family adaptation. Canam (1993) suggested that parents adopted coping strategies in order to face the task of accepting their child's condition. One coping strategy was through the process of assigning personal significance to the condition and by finding an explanation for the condition from past family history. Another coping strategy might be the family's religious beliefs that brought unity and a logical reasoning to the situation. It was also helpful if the family took an optimistic view so as to nurture hope for the future of the family. By perceiving the child's condition as a challenge that needed to be overcome, the family could find strength. Sometimes by comparing their family to other families in a similar situation assisted them in highlighting their positive outcomes.

A possible resource that was available when dealing with stress within the family was the "self" which included the ego strength, adaptability, trust, crying, and self-esteem. Another resource that helped deal with stress was the marriage, the effectiveness of which depended on its duration, the marital happiness, the age of the partners and their religious beliefs (Groce and Zola, 1993). The extended family, including parents, siblings, and in-laws could assist in dealing with a stressful situation. It was beneficial if the family was aware that there was financial support if they needed it. Lewis *et al.* (1998) suggested that the family's adjustment depended on social resources, community support and the family's outlook concerning their situation.

A study by Bouma and Schwetzer (1990) compared stress patterns of three groups with a total of twenty-four mothers. One group consisted of mothers of children with a chronic physical illness, cystic fibrosis, and another group of mothers of children with a psychological disorder, autism, and the third group were mothers of children without a physical or psychological disorder. While different patterns of responses were recorded with the use of a questionnaire, autism appeared to cause the most stress. The results of this study could be applied for the development of family intervention programmes.

A study by Bender *et al.* (2000), conducted at multicentres included a randomised clinical trial in 8 cities in North America. A total of 1041 children, aged 5-12 that were confirmed as having mild to moderate asthma were included in the study. Several other studies had previously been carried out but with inconsistencies. These authors claimed that there

were two methodological shortcomings to the other studies, first, the previous studies had relied on parental reports without physicians' verifications of the findings. Second, many of the participants were a "sample of convenience" and single-site cohorts of small samples had resulted in different outcomes. In their own study, the authors examined the illness-adaptation in children with mild to moderate asthma. The hypothesis was that these children would have difficulty with psychological adaptation depending on the functioning abilities of the family.

The conclusions were that little evidence was found to indicate increased psychological difficulties among these children and their families. They further explained that compromised psychological adaptation could occur not only from chronic illness but also from other types of extreme stress such as poverty, war, natural disasters, and physical disabilities. It appeared that even with these types of stress, children could still be happy and well adjusted. This seemed to depend on the "protective" factors such as the child's temperament, the strength of the family, and the external sources of support. One of the weaknesses of this study was the fact that the children were chosen very carefully which meant that the results could not be generalised. Also, another one was that only children with mild to moderate asthma were included and those with severe asthma were excluded.

Knafl *et al.* (1996) found in their study that the families that they described as "thriving families" had adapted by using the "normalcy theme". These families considered themselves to be the normal family. This study included many two-parent families whose children had diabetes, 35, juvenile rheumatoid arthritis, 6, children with renal problems, 7, children with asthma, 5, and the other 9 children had a variety of conditions. This article explained that not all families having a child with diabetes thrived in caring for their child. It appeared that the unsuccessful parents had not worked as a team but as two separate individual people. These parents disagreed on how to care for their child, which seemed to cause the family to be less successful in its adaptation. It was suggested that the results of this study could be useful for nurses to judge a family's level of adaptation. The lack of sufficient knowledge of family adaptation found in nursing literature was the reason for Knafl *et al.*'s (1996) study.

Burke *et al.* (1999) developed a guide to be used by nurses to identify stressors occurring in the lives of the caregivers and to distinguish between the issues that required

immediate nursing interventions while noting others for the future. An important social support found in this study was that other parents were a dependable source of understanding and support due to their own situations.

Maladaptive emotional responses must be avoided according to Price (1990). A nurse's goals should be to provide holistic care which includes assisting parents to work through the process of grieving or mourning (Hatton *et al.*, 1995). The parents suffered many losses when they received the news of the diagnosis of a CHP. Among the losses that parents felt was the loss of a healthy child, the loss of their lifestyle, and sometimes most upsetting to fathers was the loss of the secure feeling that they could protect their child (Lowe and Lyne, 2000). However, an argument against such feelings of loss was made by Kearney and Griffin (2001) and Van Riper (1999). They found that some parents disagreed with the literature that caring for a disabled child was such a "tragedy". These parents described both "joy and sorrow" in their experiences.

Van Riper (1999) described a study concerning parental responses to caring for a child with Down syndrome. Sixteen parents were interviewed to describe their experiences. Initial sources of uncertainty found in their adaptations were: the unexpected diagnosis of Down syndrome, worries about the future, doubt of their ability to cope and the initial responses of health care professionals. Later, their concerns were educational programs, the child's future and the child's health condition, which coincided with the findings of Monsen (1999). They claimed many positive consequences from their relationship with their child which included: a closer family relationship, understanding the true meaning of unconditional love, putting things in proper perspective, and appreciating individuality.

Also concerning "stress" were the concepts of sorrow. Two major models had been used to explain parents' reaction to their children's illnesses: the time-bound model and the chronic-sorrow model. The time-bound model claimed that the family adapted and accepted the child's illness. The chronic-sorrow model contended that the parents learned to adapt to the illness but never totally accepted the illness. Chronic sorrow was a natural reaction to a tragic event and it varied from parent to parent (Hainsworth *et al.*, 1994). According to Lowe and Lyne (2000) some parents denied feelings of chronic sorrow, which prevented them from dealing with their situation

2.4.6.1. Time-bound Theories of Grief

Price (1990) concluded that researchers disagreed concerning the many time-bound theories of grieving. Their main disagreement was as to the number of “stages of grief” that it takes for a person to go through in adapting to an altered body image. Four stages were identified by Grunbaum (1985): shock, defensive retreat, acknowledgement and adaptation. Five stages of grief were identified by Kubler-Ross (1970), the first two were “denial” and “anger”. The denial stage was when the patient refused to believe what was happening, the next stage was anger, during which the patient felt deprived of the organ/limb or body function. This was usually followed by the “bargaining stage”, where the individual made a deal with fate and asked to be spared the body alteration. Difficult to overcome was the stage of “depression” and if it was overcome, the final stage of “acceptance” was achieved. If the final stage was reached, it was believed that the individual had come to terms with the alteration and had accepted his new body image.

Suggesting other stages, Casarett *et al.* (2001) included anticipatory grief, grief, acute grief, normal grief, and complicated grief. They suggested there were clear opportunities to offer support throughout these stages that would enable the parents to cope with the loss. However, in disagreement with the stages-theory was Worden (1995). He suggested a theory of bereavement counselling which disagreed with the use of stages since he claimed they implied passivity on the part of the patient. He saw grieving as a number of phases accompanied by a task that needed to be completed in order to adapt to a loss, be it a person or of a body part (Hasler, 1996). The four phases along with the tasks that must be completed are presented.

Realising the loss is the first task which was usually accompanied by feelings of denial and attempts to bargain, which are similar to Kubler-Ross’s first and third stages. The nurse’s use of communication skills assists the patient in expressing his feelings concerning his loss (Worden, 1995). A cathartic process is the second task according to Worden, the grief needs to be experienced and involves the release of emotions and pain. The nurse assists the patient in going through this task. The third task involves the patient’s adaptation to his new role by recognition of his weaknesses and strengths and what he can and cannot accomplish. This task is the most difficult since it involves readjusting to his new image, appraising it, accepting his weaknesses and then continuing with his life in as normal a way as possible. The fourth task requires the patient to look

forward to his life in a positive manner by accepting the loss of the body part or function. He needs a positive attitude to begin this new way of life. At this stage the nurse evaluates if the patient and his family are adapting or if they need a referral to a specialist counsellor.

Cutcliffe (1998) identified six reactions seen in the process of grieving, which were alarm, searching, mitigation, anger, guilt, and gaining a new identity. Parkes (1996) described these processes as a series of clinical pictures with common features blending in and out of each other. Cutcliffe (1998) maintained that time-bound sorrow was predominant in the literature and that bereavement counselling must lead to a resolution and to acceptance in order to be successful. However, the believers of 'chronic sorrow' argued this notion (Hainsworth *et al.*, 1994; Parkes, 1996).

2.4.6.2. Chronic Sorrow

Authors described "chronic sorrow" as another form of grieving a person's death or the loss of a body part or function (Marris, 1993; Parkes, 1996; Teel, 1991; Tinlin, 1996). In experiences of chronic illnesses, Hainsworth *et al.* (1994) claimed that not achieving the acceptance stage was normal since the child and his family had an on-going loss. Grief in these instances included periods of remission and intensification of grief symptoms (Dashiff, 1993; Hainsworth *et al.*, 1994; Teel, 1991; Tinlin, 1996). Shock, fear, anger, idealization, guilt, depression, physical symptoms, withdrawal, hostility, lowered self-esteem, despair, anxiety, blame and insecurity were the emotional responses to changes in body image (Marris, 1993; Parkes, 1996; Worden, 1995). Having a child diagnosed with a chronic ailment had been likened to the grief reactions experienced as a result of bereavement through death (Parkes, 1996).

Sometimes families appeared to be successfully coping but at the same time they suffered from negative emotional responses and, thus, their reactions fit the description of chronic sorrow (Hainsworth *et al.*, 1994). It was reasonable to assume that children and their families were reminded of their losses on a daily basis, but also on milestone occasions, such as birthdays (Eakes *et al.*, 1998).

There were various studies concerning parents of diabetic children by Anderson and Auslander (1981), Almeida (1995), Gallo (1990), and by Rossman and Rosenberg (1992).

Studies of outstanding quality were those by Lowes and Lyne (2000), Hatton *et al.* (1995), and a study conducted in Greece by Coclami and Bor (1993). These studies' findings expressed a deep need for families to obtain more emotional support. The difficult situations these parents faced on a daily basis pointed out that support was needed to help them cope with trying to survive while caring for their children's conditions. A literature review by Meleski (2002), as mentioned earlier, examined ways that nurses helped families cope with CHP, including diabetes.

Lowes and Lyne (2000) studied the chronic sorrow in parents of children with newly diagnosed diabetes. They described chronic sorrow as functional adaptation to but not acceptance of their child's diagnosis. These parents felt a recurring sadness, interwoven with periods of neutrality, satisfaction and happiness. Lowes and Lyne (2000) agreed that there were losses other than death, such as the loss of health, which can be regarded as bereavement. In these cases parents felt grief since they felt they had lost their once healthy child, along with their own lifestyle. Another loss for them was that they could no longer protect their child from danger (Edwards, 1987; Johnston and Marder, 1994; Karp, 1993; Lowes and Lyne, 2000).

A study of parents' perceptions of caring for an infant or toddler with diabetes revealed that the parents had immense feelings of responsibility for the life of their child every minute of the day and night (Hatton *et al.*, 1995). This study included eight two-parent families who had been caring for their young child's diabetes for at least two months. The average age of the child at diagnosis was 18 months old and at the time of the study the average age of the child was 13 months old. Couples were interviewed together and the interviews lasted from 2 to 3 hours, it appeared that the participants were anxious to tell their stories. Extreme stress was revealed in this study. This stress was caused by the fear of maintaining the complex management regimen, carrying out the painful and invasive procedures, and the many losses concerning the child and family life, and their social isolation. These parents had various fears, they were afraid to trust others to care for their child, they were worried about their child's future and about maintaining his safety.

Their accounts were retrospective interpretation of the phases the family had passed through along with their current phase. The report was in three phases: diagnosis and hospitalisation, caring for the child at home, and long-term adaptation. A positive finding

of this study was that fathers reported heightened bonding and a better father-child relationship. By both parents participating in the interviews they learned more about each other. The interviews helped them gain insight into how their partner was feeling, they heard information that they had not shared with each other before. They claimed that being interviewed was therapeutic because someone listened to them empathetically. Hatton *et al.*'s (1995) study results indicated that effective nursing support and intervention made a critical difference to the outcome of the family's adaptation. The parents suggested that there was a need for more information to be provided and for long-term home-based support to be offered. The researchers concluded that more health care planning, interventions and research were needed since diabetes in a young age group was increasing.

Coclami and Bor (1993) conducted an exploratory pilot study to investigate the family relationship and the educational resources available for Greek insulin-dependent diabetics. Twenty patients, all younger than thirty years old, and their parents were randomly selected to answer a questionnaire addressing the impact that diabetes had on their relationship and their daily activities. At first the parents and children were interviewed together but this had to be changed because the children could not speak freely in front of their parents. As a result, each person was interviewed separately. This study revealed that limited sources of education were available to Greeks and that most diabetics had not seen a psychologist or counsellor for assessment. Greek parents were very protective of their children. A Greek parent would be offended if a nurse suggested that any member of their family should seek professional help from a psychologist or psychiatrist, they would feel that suggesting such a meeting indicated that mental illness was suspected, according to Tripp-Reimer and Sorofman (1998).

The children were usually content except they often complained that their parents were too overprotective. It must be remembered that this was also a common complaint among healthy Greek children. This study mentioned that Ohwovoriola and Omololu (1986) compared the personality structure of diabetics with good management of their illness in comparison with those who showed poor management. They concluded that diabetic children with good self-esteem had better control over their illness. They described diabetes as a major health problem, affecting 2-4% of the population of all countries.

They suggested it was important to properly manage this illness in order to prevent long-term complications.

Koski and Kumento's (1977) study, as cited by Coclami and Bor, when discussing diabetic control, described four family types. The four types of families were the "normal" nurturing family, which encouraged independence, and the second type was the "over-nurturing" family, which encouraged dependence. The third type was the family that "recognised the child's needs" but could not provide them and the fourth type was the family who "did not fulfil the child's needs" because they did not recognise them.

It was suggested that the stability of a marriage influenced how well the children managed their diabetes. Studies, according to Coclami and Bor (1993), showed that children with better control of their diabetes were found in families where the mothers were satisfied with their marriages, and in families that showed stability and lack of conflict. This agreed with the findings of Rossman and Rosenberg (1992). The higher level of family stress, the poorer control the children had on their diabetes according to Rossman and Rosenberg (1992). They found that children whose families' balance was disrupted with marital conflicts were not managing their condition adequately. Accordingly, the less stressful family environment, the better the control of the illness was found, making this factor one of the most significant in the management of diabetes.

However, Almeida (1995) suggested that family members being too involved, which was called "enmeshment", often prevented the child from becoming independent. Over-protectiveness increased children's stress responses and even led them to rebellion. Sometimes this over-protectiveness forced the children to react in a negative way which resulted in the parents feeling rejected, inadequate and reduced their self-esteem.

Another problem caused by over-protectiveness was a negative effect on the children's autonomy and competence in caring for their disease in the future. In agreement with the importance of a healthy family environment providing better management of diabetes was Anderson and Auslander (1981). They agreed that diabetic children had better control over the disease when the family provided emotional expressiveness, cohesion, unity, stability and when there was marital satisfaction on the part of the mother.

There were cultural differences, as pointed out in the study carried out by Coclami and Bor (1993), concerning Greek families. They reported that Greek families were more traditional and conservative by European standards, and did not freely show their sorrow. The Greek family was very private and wanted to project the perfect family image even when it when it did not exist. Due to these customs, it was difficult to obtain their true reaction to their child's alteration in body image. Since culture and tradition played an important role in the Greek way of life and history stated that Plato and Aristotle recommended that deformed babies be destroyed, some Greeks were made to feel ashamed if they had a less than perfect child (Edwards, 1996).

Greek parents in the study conducted by Coclami and Bor (1993) felt that nurses should provide more comprehensive information to them so that they could offer better care for their children. Information was high on the list of what the families felt they needed and had not received. They suggested that further studies to investigate stigmatisation of Greek families were needed in an attempt to improve social acceptance of these children and their families.

2.5. Social System

King's (1981) interacting system, the Social System, was made up of groups within society having the same concerns and interests, for example, the educational and health care systems. When discussing the health care system, certain concepts needed to be understood which included "organisation", "power", "authority", "decision-making" and "role" (King, 1981). These concepts were discussed according to the framework based on the findings of the relevant literature.

2.5.1. Stigma and Chronic Conditions

Erving Goffman (1963) contributed to the connection of social theory to health and health care knowledge. He wrote an influential book dealing with social stigma called *Stigma* (1963). He described "impression management" since he believed that people place so much importance on how others see them that it causes them to play-act, by acting out roles in front of others and not being themselves. Goffman defines stigma as when the individual does not meet the stereotyped expectations of the society in which he lives. These persons are considered less than normal resulting in discrimination and in

rationalisations for these discriminations. The person who has the stigma slowly believes that he is below normal level just as society treats him. Stigma affects his social world and social interactions with normal persons since they are found to be difficult.

Sometimes the normal person pretends nothing is wrong making the stigmatised person feel more self-conscious. For these reasons, contacts are avoided, leading to depression and can result in social isolation.

However, Goffman (1963) names two groups, the “own” and the “wise” groups, in which the stigmatised are seen as normal. The one group, the “own” group consists of those with the same problem, such as support group members, and the second group is the “wise” group, this includes nurses since they have the knowledge of the health problem, offer sympathy and have accepted the stigmatised.

Stigma is identified by society according to Goffman (1963), however, Schneider and Conrad (1980) and Hehir (2002) state that stigmatisation depends on whether or not the individual sees himself in that way. Hehir (2002) believed that society should not devalue the individual when that person does not live up to society’s standards. He suggested that the society should not concentrate on the negative attributes, but should take into consideration the person’s unique abilities, personality traits and life circumstances.

Not all problems that cause social stigma are apparent, thus, two groups exist, the “discredited” and the “discreditable”. The former being apparent while the latter are not immediately apparent. For the latter group there is the problem of trying to pass themselves off as normal with the fear of an incident occurring which will identify their problem (Charmaz, 1991). Stigmatised persons react in a variety of ways, such as they may ignore the incident, identify with people who have the same health problem, join a group, or speak out against the rules. Others try to conceal the signs of the stigmatising feature, or make the defect seem insignificant. The length of time and nature of the condition, along with personality characteristics, have an influence on how they deal with the stigma (Joachim and Acorn, 2000).

A person with an invisible condition may conceal it or they have two choices if they wish to disclose their condition, either by “protective” or “spontaneous” disclosure, according to Charmaz (1991). The former being able to reveal as much information as they wish,

when they wish. The latter being when they reveal their condition without thinking about it. However, Troster (1997) suggests there is “preventive disclosure” in which the person tells others in order to prevent a stigma that could occur if the others were to find out by accident, such as in epilepsy. People may feel it is better to lightly mention their controlled condition just in case he might have a seizure. According to a research carried out by Joachim and Acorn (2000), stigma and disclosing appeared in the literature, but many of the sources were 20 years old. This appears to be a subject that needs further study since there have been many societal changes since then.

2.5.2. Education

Hehir (2002) examined how society made assumptions which influenced the education of disabled children. He included relevant research, interviews with disabled children and their parents. He suggested that “ableism” discriminated and separated people with mental, emotional and physical disabilities and that this devaluation showed disregard for people with disabilities. Due to this ableism perspective, social attitudes asserted that it was better for a child to “walk than roll”, “speak than sign”, “read print than read Braille” and to associate with non-disabled children. It appeared many educators expected and preferred disabled students to perform in the same manner as non-disabled students. However, it was argued by Ferguson and Asch (1989) as cited by Hehir (2002), that too much attention from educational and developmental services upon the characteristics of disability denied these children many opportunities that were taken for granted by non-disabled children. It was argued that disability was so negative and tragic which taught the disabled that only by overcoming their disability would they be valued.

“Ableism” had a negative influence on education and reinforced prejudice against disabilities, which contributed to inadequate education attainment and employment. It was suggested that the child spending too much time away from important lessons while trying to learn to read Braille or learning sign language had educational deficits. In this way, “ableism” assumptions may have handicapped disabled children. This article went on to give a history of the existence of schools for the deaf, which were considered very important at one time.

Hehir (2002) mentioned that allowing deaf or disabled children to build on their own inherited strengths could ultimately make them better able to compete in the real world. It

was also pointed out that teachers made an attempt not to label students in order to help them to avoid being placed in inferior special education schools. Some of these schools avoided challenging disabled children, which meant that the children failed to learn the material that they could learn based on their intelligence. This dilemma for parents and educators would not exist if schools carried out research-based practices and if there were improvements in special education programmes.

2.5.3. Health System

2.5.3.1. Organisation

The Hellenic National Health Care System included hospitals, community health centres and local support groups.

2.5.3.2. Power

“Power” was defined as having an impact on others as well as the ability to take action to regulate or manage other people. Creasia and Parker (1991) identified power as a very strong human need, beginning at the time of a person's birth, although many nurses did not recognise the importance of power to people. Power played an important role in interpersonal relationships. Patients and families found it important to have power over their treatments and goals, which emphasised the importance of nursing rehabilitation (Gibson, 1999).

According to Cresia and Parker (1991), a person's power existed as long as the other person cooperated and conformed to the prescribed pattern, thus, there can be a conflict between roles of nurses wanting to offer support and parents not wanting to conform to the role of the nurse having this power. Control was the successful manipulation of the environment and the behaviour of self and others in order to obtain one's objectives. It did not really matter if the parents had control, but what was important was that they perceived that they had control. The parents wanted decisional control, which was the ability to choose between different courses of action according to Gibson (1999).

Knaft *et al.* (1996) reported that families felt lack of control over their children's conditions due to increased psychological stressors because of their child's altered body image, fear of their child's death, role disturbances in their social life, and life-time changes which made them suffer from feelings of powerlessness. This powerlessness led

to anxiety, depression and hopelessness. Nursing strategies that empowered parents included providing education, an individualised approach to care, involvement of them in caring for their child and encouraging parents to articulate their feelings by employing counselling skills.

2.5.3.3. Authority

Giddens (1984) identified “authoritative resources” as the ability to make other human beings do what we wanted them to do. This ability provided the basis for social power. However, Giddens (1984) explained that when a nurse was acting in a subordinate fashion, such as pushing the record cart on rounds while the physician was acting in a superior way it was because the nurse accepted the situation and had not objected to it. Our social systems have developed from social conduct that have been reproduced chronologically across time and space (Giddens, 1984).

Porter (1994) described studies in which parents questioned the authority of health care visitors. Health visitors tried to persuade parents of healthy children that they visited to conform to the health care standards that they believed were proper. However, it was suggested that these health care visitors had not taken into consideration the parents’ perceptions which resulted in the parents challenging the legitimacy of these health care visitors. These parents felt childcare was a skill learned by experience and they distrusted the theoretical approach. These parents did not openly question the authority of the nurses, they politely accepted their advice and then went on to ignore it. As a result of not accepting the health visitors’ authority, the parents stopped attending the clinic or they avoided conflict by concealment and deception. The parents admitted they told the nurse what they knew she wanted to hear, which was a way of neutralising the power of the health care visitor.

Porter (1994) described the newer strategies in nursing such as advocacy and primary nursing. He interviewed nurses to evaluate the quality of their relationship with patients since these newer strategies were implemented. It was discovered that since the taboo of talking to patients had ended, the patients felt more comfortable talking to nurses, instead of the previous one-way interactions that used to take place with the nurse in the authoritative position. As a result of these freer interactions, patients felt comfortable asking questions, which meant that nurses needed to be more knowledgeable and up to

date with their information. Nurses felt they were expected to explain the diagnosis, the reasons for treatments, and the effect of each medication. Patients expected to participate in planning their care plan after negotiation with the nurse. A limitation of this study was that Porter (1994) restricted this empirical investigation to interviews with nurses and failed to include patients in his evaluation of the nurse-patient relationship.

2.5.3.4. Decision Making

According to Coyne (1995) and Swallow and Jacoby (2001), decision making was an activity that many parents felt they should take part in concerning health care situations. Many parents were more interested in this type of control than having control over activities of daily living and their physical environment. They found it important to have a role in deciding certain diagnostic tests, treatments, and surgery. However, not all patients felt this way according to Eriksen (1995), since some parents considered themselves incapable of making the best decisions for their child's future and did not want the responsibility.

2.5.3.5. Role

King (1981), defines that a "role" is a set of behaviours reflecting personal, social and occupational fields. "Roles" are classifications of behaviour according to a position held within a social system where the rights and obligations are identified. If the parents' and nurses' expectations of a role are different, it is called a role incongruence, which could interfere with a nurse properly fulfilling her role (King, 1981).

2.5.3.6. Nursing role and medical model

There are two competing theories used to study roles, the structural-functional approach and the symbolic interaction approach. The structural-functional approach connects individuals to a social structure and concentrates on their share of labour within that structure. In other words, the individuals are considered according to the contributions that they make towards society. In this perspective, the norms and values are attached to the nurse's position and are handed down from generation to generation, with adaptations made as the social structures changed (Giddens, 1993).

The second perspective is the symbolic interaction approach which deals with the interaction between people within the social system. Symbolic interactionism discusses

the dynamics on interactions between individuals to explain the meanings that these actions have for the individuals. It is argued that this theory of George Mead (1863-1931) is based upon the American culture of the individual in contrast to the European ideas of social structures. Mead defines the importance of “self” as the ability to reflect on one’s mental processes and to have “inner conversations” which enables humans to think about their responses. Mead’s collaborator, Charles Cooley (1864-1929) argued that “self” developed through the incorporation of the views of others, that “self” is not isolated. This relationship between social groups and the individual allows the individual to apprehend, interpret and incorporate the views of others, which is the ability to participate in symbolic interaction. An act becomes symbolic when there is a shared meaning attached to it. The meaning a person has for something is determined by the ways in which other persons react toward it according to symbolic interactionism (Porter, 1998).

In this approach meaning is given to acts and symbols are used to construct the nurse’s role, but the symbols need to have the same meanings to all participants in order for successful communication to take place. This is seen when a new graduate is orientated, she learns the staff nurse role by observing her preceptor’s actions (Cresia and Parker, 1991).

Both perspectives are valid, the structural-functional perspective is useful in studying the formalised aspects of the nurse’s role. The symbolic interaction perspective is useful concerning the interdependent nature of nursing roles and the process of acquiring behaviours specific to a given nursing role (Cresia and Parker, 1991).

Nurses’ roles were discussed in most of the articles, describing the need for them to offer more support. It is important to include not only the nurse’s role as based on society’s development, but also the medical role. In the western world the traditional approach to the diagnosis of illness is carried out using the medical model. In this way the physician focuses on the physical health problem and tries to solve it by using a problem-solving approach. This includes the medical history, physical examination, and diagnostic tests to determine the specific illness and its treatment. The medical model is interested in the physical and biological aspects of diseases, and is known for its dominance over the nursing profession. In contrast, although nurses are dominated by the medical profession, they perceive the patient as a social person relating to his environment and that nursing

care is considered based on a nursing assessment that assumes many causes for the patient's problems (Porter, 1998).

Nursing examples of symbolic interactionism in interactions were identified by Hewison's (1995) study of nurse-patient interactions. He studied nurses interacting with elderly clients and identified four different interactional strategies that nurses adopted in order to have power over their clients. The first strategy was "overt power", the nurse making decisions without asking the client. This required an expectation on the part of the nurse that the client would accept her being in control. These patients interpreted the nurse's position of authority as a legitimate one.

The second strategy was "persuasion" in which the nurses cajoled patients to act in ways in which they did not want to. Nurses had a privileged position when negotiating. The third strategy was "controlling the agenda", this most common way was carried out by asking the elderly patients a series of questions which were controlled to give the proper answers. The final strategy was "terms of endearment" by talking sweetly to the elderly patients, the nurses were able to ensure their cooperation. This demonstrates the importance of symbolic interaction as a means of understanding the world (Porter, 1998).

In contrast, Parsons' (1951) structural functionalism viewpoint defines any action within a role can be classified as either "instrumental" or "expressive". Parsons' viewpoint was that social order does not depend on self interest, but through socialisation where the individual learns to accept the common values and goals of society. He argued that social expectations are incorporated into actions through learning the social roles. In this way we all play various roles, when these roles are generally accepted they become institutionalised, which leads to a stable society. He argued that it was possible to classify the values that were the foundation for the roles, and categorised the values concerning any action within a role as either "instrumental" or "expressive." These are very descriptive of both the nurses' and doctor's roles.

"Instrumental" actions are goal orientated which lead to an identified end. However, expressive actions are performed on their own, which are an end in themselves. Parsons classified the "instrumental variables" with "advanced" societies, public life and men, which included physicians who have the power to dominate the nursing profession,

according to the medical model. Parsons classified the “expressive variables” with “primitive” societies, private life and women, nurses were concerned with caring and they were considered weaker and willing to be dominated by the medical profession. Within the two groups, five alternative sets of “pattern variables” were identified that Parson believed structured all social actions.

The first set is “affectivity” and “affective neutrally.” This refers to the degree of emotions involved. Nurses become more emotionally involved and caring, thus they are affectively involved while physicians, who maintain their distance from their patients have “affective neutrally”.

The second set is “collective orientation” versus “self-orientation”. In “collective orientation” one puts the interest of the group before his own interest, which is seen as a nursing role. The “self-orientation” puts their own interest first, physicians could be included in this group.

The third dichotomy of pattern variables are “particularism” versus “universalism.” “Particularism” suggests that people respond differently to others depending on how much they have in common with them. In “universalism” people act towards others based on general principles, not as they are as individuals. The physician uses his knowledge for all patients, an example of “universalism.” In contrast, nurses act differently to each patient and his family depending on their needs which is seen as “particularism”.

The fourth pattern variable is “ascription” versus “achievement”. With “ascription”, people are given, or not given, status according to their position which could include nurses. “Achievement” is the means by which physicians achieve status as a result of their long-term professional studies.

The fifth and final variable is “diffuseness” versus “specificity”. The diffused role covers a wide range of interest, this would include nursing since it offers many roles such as offering support, physical care, counselling skills, and nursing rehabilitation. The physician would be classified under “specificity” since they are interested in diagnosis and treatment, which is included in their specialty.

Davis (1995) identifies the medical profession as a product of the masculine code. Parsons' (1951) development of the medical role is that nursing is expected to be the feminine adjunct to this masculine profession. By taking on the feminine duties of caring, nursing allows the masculine profession to gain power and privilege.

However, Davis suggests a new nursing practice that would not be as extreme as the one identified by Parsons. She claims that nurses should be "engaged", not emotionally involved, "interdependent" and not dependent, "embodied use of self" not self effacing, "creator of an active community" and not passive, and a "reflective user of experience and expertise" and not the user of experience that nurses are now.

Mead *et al.* (1997) reviewed the literature in order to discover the nurse's role, the potential role and the current role in mental health work. Included was a look at current and future training needs, and the possibility of expanding the nursing role with opinions from patients and nurses. These authors reviewed the published literature to discover and to describe the need for nurses and their potential roles in relation to the management of emotional problems. Their literature review suggested that nurses might be able to identify patients that were at high risk to develop emotional problems such as socially isolated care givers and parents of children with a CHP. Their children's health problems were a major source of anxiety and stress to these parents.

Mead *et al.* suggested that nurses needed to offer early interventions such as offering support and counselling by the provision of information, and by offering self-help guides along with details of external agencies, such as parent support groups which offer advice and further social contacts. They identified the need for nurses to be able to recognise emotional disorders occurring to their patients throughout the health care setting. However, some nurses felt that they were incompetent and lacked the necessary skills to be able to cope with this demand. Based on this study, it was suggested that nurses were currently offering emotional support and care, but it was not being acknowledged as such. This was in agreement with Small (1995) who maintained that psychological support in care was being delivered during routine nursing tasks that have important supportive and therapeutic benefits but which had not been recognised or acknowledged.

Sapountzi-Krepia *et al.* (2001) studied the impact of scoliosis bracing on the perceptions of body image on 150 secondary school children living in Athens, Greece. These authors pointed out that the Greek nurses were judged as not allowing the parents to discuss their feelings and problems. They went on to emphasise that nurses have a moral and professional responsibility to carry out their role as advocates for patient's rights.

However, these researchers pointed out that this role was not easy in contemporary Greece due to the shortage of nursing staff and increased demands on the health care system. When working with children with altered body image, nurses were provided with an opportunity to expand their nursing role by adding the role of the health educator and counsellor. It was important for nurses to provide information to parents about how the illness and treatment affected self-image and how the parents could promote a more positive self-image for their children. It was important that nurses stress the significance of treating their children as normal adolescents, according to Sapountzi-Krepia *et al.* (2001).

2.5.4. Community and Social Interaction

Although this concept had not been clearly stated by King, she suggested that the social networks and their interactions with people influence transactions. Thus, community, an additional concept to King's framework, was important as a way of classifying friends, neighbours, teachers and others that interacted with parents of a child with a CHP.

Tripp-Reimer and Sorofman (1998) stated that within the Greek community, social status and prestige was associated with family pride and unity. Social status was measured by a family's wealth, educational achievements and accomplishments of its members, as judged by the community. The status and integrity was confirmed by other families when a family was faced with an unfortunate situation: such as poverty or parenting a child with a CHP. Social stigma and shame was brought upon the whole family if an individual suffered a misfortune, such as an illness or disability.

Galpin (1996), agreed with Goffman,(1963), and defined stigma as the devaluation by society of a person who does not live up to society's accepted standards of body image. Cresia and Parker (1991) introduced the concept of "spread" which was the term used when the public perceived an impairment as being more severe than it actually was. An

example of this was when a deaf child was considered mentally retarded, yet when he was tested, he was of normal intelligence.

Tripp-Reimer and Sorofman (1998) suggested that parents responded to stigma in many ways such as ignoring it, or, by identifying with people that have the same affliction, or by speaking out, or by trying to hide their child's altered body image, or by trying to de-emphasize the defect so that it was seen as insignificant. The length of time they had the alteration along with the type of alteration influenced how the child and his parents dealt with stigma.

Groce and Zola (1993) described how different cultures addressed issues of altered body image and that health care professionals needed to understand the social implications of CHP. They named three issues that all cultures took into consideration: 1) how the culture perceived the cause of a chronic illness or disability helped determine the family and community's attitude toward the child, 2) the life expectancy of the child determined not only the immediate care, but also the amount of effort needed in planning for future care and education, and 3) the social role given to the child and later as an adult determined the amount of resources offered to the family and the community.

Blue (1993), as cited by Purnell and Paulanka (1998), mentioned that social stigma in Greece was associated with mental illness which affected not only the person but the family and relatives as well. The mentally ill persons and their families experienced loss of friends and social isolation since some Greeks considered mental illness to be a hereditary illness in which the bloodline was contaminated. For this reason, Blue (1993), as cited by Purnell and Paulanka (1998), suggested that Greeks did not always provide truthful symptoms and in order to prevent social stigma, sometimes somatic symptoms were given to the health care professionals in an attempt to appear normal.

Concerning social stigma in Greece, abusive behaviour was rare but neglect has occurred. By neglect it was meant that institutions had not nurtured the children and had not provided adequate care, education and emotional support. According to Midgeley (1997), reporters from the UK visited Greek institutions and filmed a documentary. This reporter claimed that due to the social stigma, physically and mentally disabled children were tied to cots and kept out of sight.

This was found in two state-funded institutions, the one in Karditsa with 200 children and the other in Serres with 100 children. The public health centre, which managed both institutes, defended itself by saying that they had a policy of not rejecting any child and thus, suffered from lack of space and shortage of staff. According to this article the condition of these children's health and chances for improvement with treatment were evaluated when they were young. If it was decided that they would not benefit from treatment, they were given only the basic requirements of food, warmth and shelter for the rest of their lives. They were not stimulated or lifted from their cots for years. They received no treatment and had not even seen daylight. The film showed a pair of middle-aged mentally handicapped twins tied to their cots in the same room since they were babies. It also showed a 25-year-old woman who was physically disabled who had not left her bed for 15 years.

In 2004, George Hristakis, a top European competition dancer in a wheelchair, stated that up to 10 years ago there was a huge social stigma to being disabled in Greece. He reported that parents felt helpless and ashamed and prevented their children from participating in normal activities. His uncle is a lecturer on studies about disabilities and has campaigned for over 30 years to improve public awareness of problems concerning disabilities. Society's attitudes have improved but he claimed they were not even close to meeting western European standards, mostly due to insufficient government funding (Amvrazi, 2004).

Amvrazi (2004) introduced Panos Tsinganos as one of the founders of a popular website *www.disabled.gr* for the disabled and publishes online and in their magazine entitled '*Disability Now*', articles, opinions, statistics, research, and news of their activities, both in Greek and English. Eight thousand subscribers receive the magazine for free. Hundreds of people communicate daily online, to openly discuss issues of friendship, sexuality, family and work. Another founder, Nikos Voulgarakis, stated that the site broke through their isolation and helped them to live with dignity and independence. This article stated that the disabled in Greece must stop being treated as faulty individuals that do not deserve responsible assistance, including practical and social attention (Amvrazi, 2004).

A study conducted by Vardakastanis and Chatzipetrou (2004) at the University of Athens concluded that poverty and social exclusion should be identified beyond the monetary

poverty level. They also asked disabled persons to participate in the research in order to evaluate the main causes of their social exclusion. The results showed that 95% listed social environment and unemployment as the first cause, 85.4% listed the lack or limited access to services as the second cause, and 83.3% listed social stigma as the third cause. Other causes included were inadequate training, lack of services, lack of education, lack of funds and living in institutions.

Further discussion concluded that disabled people were more vulnerable to poverty. It stated that an inclusive education would certainly produce an inclusive society. This suggested that disabled and non-disabled children needed to be educated together. It concluded that in order to stop discrimination and prejudice, children must be educated at a young age in order to learn to respect human rights. Most disabled children could attend normal schools if given the proper support. It was suggested that if these children were excluded from normal education they were later excluded from employment opportunities. As a consequence, they became poor wage earners and faced more problems in participating in society (Vardakastanis and Chatzipetrou, 2004).

Vardakastanis and Chatzipetrou (2004) reported that there were other subtle forms of discrimination besides attitudes, information, and communication barriers. Health care professionals were often not aware of the specific needs which depended on the type and severity of the disability. This pointed out the need for disability awareness training in hospitals and nursing education courses, and that such training programmes should be developed by including the input of disabled people. Additional training needed to be given to staff members already in employment and vocational training centres so that they could provide information, guidance and training according to the specific needs and abilities of disabled people.

Other suggestions were that the European legislation should ensure physical accessibility to all public premises and provision should be made for alternate media in written and oral communications (Vardakastanis and Chatzipetrou, 2004). This would include Braille, large print, easy-to-read information, and sign language throughout Greece and the rest of Europe.

Changes in attitudes within the educational system were greatly needed along with awareness campaigns to the general public. They went on to suggest that governments could offer tax reductions to building owners that rented to disabled persons and to employers that hired disabled persons. They mentioned the need to offer jobs to disabled women, who were discriminated against both as a disabled person and as a woman (Vardakastanis and Chatzipetrou, 2004).

Groce and Zola (1993) maintained that many medical and educational professionals misunderstood the importance of early intervention and stimulation needed by disabled children. It was important not to try to console parents by telling them, as some parents claimed, to take care of the child for as long as they have him. This would lead to spoiling the child and neglecting proper long term planning for the child's future. Occasionally health care professionals encouraged parents to let nature take its course. Since these children live longer now, in contrast to the past, a plan for their future should be made concerning everyday problems, including long-term goals. These children needed plans to help with various aspects of their lives, such as training and education (Groce and Zola, 1993).

2.6. Conclusion

This completed the review of the current literature which identified the concepts involved in exploring the parents' and the nurses' perceptions of the nurse's role in offering psychological support. Many interesting studies were included but some of them investigated only the parents while other studies identified only the attitudes of the nurses. This researcher felt that including only one group would appear inadequate since the perceptions of one group needed to be verified by the perceptions of the other group. Thus, this influenced the final decision as to which method needed to be used.

Based on the Greek nursing literature many participants often identified that the nurses were not adequately fulfilling their role and sometimes the nurses even admitted that they felt too uncomfortable to do so (Amvrazi, 2004; Coclami and Bor, 1993; Sapountzi-Krepia *et al.*, 2001; Vardakastanis and Chatzipetrou, 2004). Thus, the literature review was very important since it was used to develop the aim, the research questions and the methodology of this study.

2.7. Summary

This chapter has considered the literature on body image alterations, nursing rehabilitation, the nurses' and doctors' role, counselling, stigma and cultural aspects of chronic illnesses, subjects related to caring for a child with a chronic health problem in Greece. This literature review lead to the formulation of the aim and the research questions of the current study and to the identification of data collection and analysis methods. These will be discussed in the next chapter.

Chapter III. Method

Introduction

In the previous chapter a review of the relevant literature was presented. This literature review was carried out to determine what research had already been done relating to this subject. This review of the literature will be used to guide the discussion of the results in terms of agreement or disagreement with the other studies.

This chapter will discuss the aims and the research questions, along with identifying the data collection and analysis methods.

3.1. Aim of the Study

The aim of this study was to explore the perceptions of Greek community and hospital nurses along with the perceptions of parents of children with CHP in relation to the nurse's role of offering psychological support.

3.2. Research Questions

The research questions investigated were:

1. What are parents' and nurses' perceptions of psychological aspects of care?
2. Do nurses perceive that they offered parents information, emotional support, counselling and nursing rehabilitation?
3. Do parents perceive that information, emotional support, counselling and nursing rehabilitation were offered by nurses?

The research questions were developed based on Knaft *et al.* (1996) suggestions of nursing strategies that would empower parents to assist them in coping to their child's CHP. One of these strategies is to provide education, this can be done by offering information. Another strategy is to adopt an individualised approach to care and to involve parents in caring for their child, these have been identified as the basic principles of nursing rehabilitation. Knaft *et al.* (1996) also suggest another nursing strategy is to encourage them to articulate their feelings, which can be accomplished by the nurse through the use of counselling skills.

To answer these research questions it was necessary to explore the perceptions of nurses' and to compare them with the parents' perceptions. This comparison was done to determine how well each group understood the nurse's role as counsellor, provider of accurate information, and nursing rehabilitation. King (1981) maintained that people's understanding of a particular situation was based on their "perception" of the situation. Their "perception" was formed from their past experiences which have an influence on their future behaviour. Meleski (2002), Seideman and Kleine (1995), and Gibbons *et al.* (1995) pointed out that although it was impossible for nurses to change the family's situation, they could assist the parents to cope more effectively by setting goals together and facilitating through the use of nursing skills such as communication, counselling and nursing rehabilitation. These authors have suggested that the role of primary care and community nurses should be expanded to assist parents of children with CHP.

In this study, the client or patient was referred to as the parent, such as the "nurse-parent interaction" since the child here was represented by the parent. "Role" was defined as a set of behaviours expected of persons occupying a position in a social system with rules that expressed the duties and obligations of that position (Creasia and Parker, 1991). According to King (1981), when nurses and patients disagreed on the nurse's role, the result were role incongruence which led to decreased effectiveness of the nursing care provided. Gibbons *et al.* (1995) pointed out that nursing rehabilitation emphasised goal setting and attainment. The nurse interested in providing nursing rehabilitation skills respected the importance of the child and not the illness. Goals needed to be set for the child to reach as much independence as possible, according to Henderson *et al.* (1995).

Canam (1993), Perrin *et al.* (1993), and Knafl *et al.* (1996) suggested in the literature that parents of chronically ill or disabled children experienced common problems even though their children's diagnoses differed. Thus, this study concentrated more on the perceptions of the two groups and not on the specific diagnoses.

3.3. Research Design

In order to conduct this scientific inquiry it was necessary to determine which research paradigm was of importance to the investigation. According to Streubert and Carpenter (1999), the researcher is required to have an understanding of the philosophical underpinnings of each paradigm in order to produce a credible study to which others can apply the results. The philosophical underpinnings of each paradigm had influenced its evolution and implementation in today's research. These paradigms, or models, included philosophical assumptions, goals and purposes. The two major paradigms used in this nursing scientific inquiry were based on the naturalistic philosophy and the positivist philosophy. The qualitative paradigm was based on the naturalistic philosophy. The quantitative paradigm, or the traditional scientific method, was based on the positivist philosophy.

Faced with the pros and cons of both paradigms, the deciding factor was presented by Burns and Grove (1997) as they described the possibility of using both the above methods to increase the validity of a study. Also, Morse and Field (1995) endorsed this method since they felt both methods were compatible and each contributed to the development of nursing knowledge. Morse (1991) reported that the use of different kinds of research methods complemented each other, enriched the research and enhanced its reliability. Thus, the research design used in this study was two-fold: a quantitative and a qualitative method, which Begley (1996) referred to as across-method triangulation.

This multidimensional approach was used to offer more information and to provide better clarity as Fielding and Fielding, (1989), cited in Streubert and Carpenter (1999), suggested. They pointed out that this strategy should be used to enrich the data and to offer better understanding, while at the same time counteract the limitations of each paradigm. Robertson (1994) agreed that through triangulation, the data were richer and complemented each other, comprising a whole, by describing the topic of interest in a more holistic manner.

Denzin (1989) identified four types of triangulation methods which were described by Burns and Grove (1997). These four types of triangulation were "data" (time, space, person), "methodological", "investigator" and "theory", or a combination of these could be used.

Kimchi, Polivka, and Stevenson (1991) named these four types but added a fifth type, which was “analysis triangulation”. Burns and Grove (1997) called a combination of more than one type a “multiple triangulation” which was chosen to be used in this study. Out of the five choices previously mentioned, two were chosen, the others were excluded for various reasons: the “investigator triangulation” needed two or more researchers, the “theoretical triangulation” required all theories to be studied and pitted against each other, and the “analysis triangulation” required the analysis of data in two or more ways to evaluate the similarity of findings. Over all, it must be mentioned that these other types were excluded since they would not facilitate in answering the research questions.

In this study the “data” and “methodological triangulations” were used. The “methodological triangulation” was used by including both the qualitative and the quantitative paradigms. The other type used was “data triangulation”, this included more than one source of data (Denzin, 1989), which meant collecting data from two levels of persons, the community and hospital nurses and the parents (Burns and Grove, 1997). In this way one level, the parents, was used to validate the data from the second level of persons, the nurses. By this method, “data triangulation” was used to contribute to the rigour of the qualitative study in order to provide a more holistic understanding of the phenomenon being studied.

Simultaneous triangulation was used to extrapolate the findings of the quantitative and qualitative research methods used. In regards to the participants included in both research methods, the qualitative design was implemented first and then on the same sample the quantitative design was implemented as endorsed by Morse (1991). She maintained that in circumstances where the quantitative measures were standardised, such as with the use of a questionnaire, the qualitative approach could be used first followed by the quantitative. Thus, the same sample was used to reflect on the issues that arose from the literature review. The non-experimental study of using surveys was considered an excellent means of exploring and comparing the parents’ and nurses’ perceptions of their interactions. An experimental research was ruled out since it was of no use in answering the research questions.

However, not all researchers agreed on the use of triangulation. As cited in Burns and Grove (1997), Phillips (1988) claimed that the two methods were incompatible because they were based on two different philosophical perspectives and most researchers had been trained in only one research method. Sandelowski (1994) agreed with Phillips that there were many problems using both methods in the same study.

Mitchell (1986) pointed out that most problems were concerned with data analysis. Among the problems were how to combine numerical data with linguistic data, how to interpret the results, how to evaluate data sources and whether or not each method should be considered equally sensitive. Morse (1991) maintained that both methods could not be equally counted in a research study. This study was driven by a qualitative method to study the human experience and a complementary quantitative component was incorporated in an attempt to more carefully explore the phenomenon and to counteract the limitations of both paradigms. Mitchell (1989) identified four principles of importance which this researcher took into consideration. These four principles were to include clearly focused research questions, to use the strengths and weaknesses of each method to complement each other, to choose methods according to their importance in studying the phenomenon, and the fourth principle was to check that the above three points were being maintained throughout the study.

Qualitative research was used here to investigate this complex, under-researched subject in Greece in order to better understand both views of the situation. In the argument between quantitative and qualitative methods, Dempsey and Dempsey (2000) suggested that some authors wanted the qualitative researchers to develop a more quantitative approach to make their results more reliable. However, Smith (1996) suggested this could be wrong since each method was useful in its own way. Although quantitative and qualitative methods had different aims and assumptions, they were both useful methods according to Mays and Pope (1995). Both types of studies conducted here concerned a problem that was researchable and that the answers were not already known as was recommended by Dempsey and Dempsey (2000).

The naturalistic paradigm appealed to the researcher, which according to Dempsey and Dempsey (2000) had a set of five interrelated philosophical assumptions: ontologic, epistemologic, axiologic, rhetorical and methodologic. These assumptions differed from the positivist's five assumptions. In the naturalistic paradigm, the ontologic assumption, or the nature of reality, was that reality was subjective and developed by the subjects in the study. The epistemologic assumption focused on the findings being created by the researcher interacting within the research process. Axiologic assumption was that the research was subjective and value-laden and recognised that values and biases were present. Rhetorical assumptions were written in a literal, informal style composed of qualitative terminology. The methodological assumption consisted of the inductive reasoning processes. In this method the entire phenomenon being studied emerged during the research, which provided a more holistic approach.

According to Carper's (1978) framework on "ways of knowing" in nursing, as cited by Streubert and Carpenter (1999), four fundamental patterns were identified as important for the researcher to understand since they were the basis for the decisions made during the planning and execution of this research study. These patterns were empirical, aesthetic, personal and moral knowing. Empirical knowing was the positivist tradition of science based on facts that explained and controlled the phenomena, this provided objective data, measurements and generalisability. Aesthetic knowing provided a framework for this qualitative research since it required recognition of patterns and not an explanation of the facts. This type of knowing was not interested in the facts that were controlled and generalisable (Crotty, 1996; Streubert and Carpenter, 1999).

Personal knowing required the researcher to know herself and to use her intuition. This meant that the researcher needed self-awareness concerning her beliefs as an essential part of fully discovering the phenomena being studied. The researcher needed to accept the "self" and to identify her feelings and then to "bracket" them to make the study and results as objective as possible. The fourth way of knowing was moral knowing which was based on one's traditional beliefs and code of ethics, this was important to this research when decisions concerning right and wrong needed to be made.

Ideas of knowing were also discussed by May (1994) and Sandelowski (1994). May (1994) described her idea of “*abstract knowing*” as “*magic*” similar to the ideas of intuition as when the researcher becomes aware of pattern recognition which allows insight into understanding the studied phenomenon. Sandelowski (1994) recognised the art, as well as the science of nursing, which compared to Carper’s (1978) description of aesthetic knowing according to Streubert and Carpenter (1999).

This researcher was in the dilemma of deciding which method to use in the qualitative portion. Qualitative approaches provide rich, detailed narrative reports concerning perceptions, understandings and descriptions by participants who had experienced these events (Smith, 1996). Several methodological approaches were investigated and rejected for their limitations to the specific context that would be investigated, but, also because of the limitations of the methods themselves.

Examination of the qualitative methods in the literature showed conflicting opinions and unresolved issues concerning phenomenology, grounded theory, and ethnography. Two additional methods, action research and historical studies, were mentioned as more recent methods by Dempsey and Dempsey (2000) and Streubert and Carpenter (1999). Action research, the method of implementing a new nursing strategy into practice was not used since this method did not facilitate the answering of the research questions and historical research was also rejected for the same reason.

Grounded theory was considered as a possible method to use in this research study since it included collection, coding and analysis of data in a field setting. This method is used to generate theory (Nieswiadomy, 1987) by “grounding” or creating the theory based on the data collected. The data are collected by various methods such as interviews, observations, and questionnaires. The researcher places the data in categories and concepts are developed which are tested quantitatively or qualitatively. As hypotheses are rejected, the data are continued to be compared to the theory and, thus, tested again and based on the known data the theory is modified (Cutcliffe, 2000; Dempsey and Dempsey, 1996). However, Denzin and Lincoln (1994) argued that by being interviewed, the participants are changed and, therefore,

would present a different picture when approached a second time for verification. It was suggested that they would not express the same feelings after having had time for reflection. Also, since this present study concerned such a sensitive and emotional subject, it would be considered unethical to ask these parents and nurses to verify what they had said, thus, this method was rejected (Denzin and Lincoln, 1994).

Another method considered was ethnography. Ethnography, derived from the Greek word “ethnos” meaning nation (Higgenbottom, 2004), is a useful methodology for studying the culture of a small group of people in their everyday environment as described by Hammersley (1992). However, there were limitations to this method since one could never fully understand and explicitly define meaning to a cultural group. Even one that was within the culture being studied could not fully pull away from it so as to view it from a different perspective. Ethnography was considered since the study included the Greek culture and several subcultures such as nurses and parents of chronically ill or disabled children.

However, ethnography was rejected because it included participant observation as a method of data collection. Participant observation of the interactions between the nurses and the parents would involve the researcher taking up the role of the observer in the health care setting while care was being offered to these children. The issue that arose was that of the justification of the observer/ researcher within the setting and, thus, if the observations were to be overt or covert in nature. This involved the nurses being observed having knowledge about what was being observed in the overt scenario which would create a significant limitation to this approach. The nurses’ awareness of being observed would perhaps alter the true situation. The use of covert observation created problems of obtaining ethical approval.

There were limitations of ethnography in terms of the researcher’s bias, time limitations and the difficulty in obtaining ethical permission, thus, this method was rejected. Kwanson-Kauffman and Schonwald (1998) pointed out that grounded theory and ethnography differed from phenomenology even though they all included the subjective experience of the informant, but in phenomenology it was the primary concern. Thus, in order to find out about the “lived experiences” of the parents and the nurses, a phenomenological approach was used

(Talbot, 1995). Field and Morse (1996) maintained that in this way, the individuals' perspective on their lived experiences was focused upon.

3.3.1. Phenomenology

After careful analysis of the various methods available, the researcher decided to use the phenomenological method since it was often described in the literature as a useful method when the focus of the study was on the lived 'phenomena' experienced. Sorrell and Redmond (1995), Bachelor (1995), Rashotte *et al.* (1997), and Krasner (2001) reported that this holistic approach gave emphasis to the whole experience of the subject, giving the participant the opportunity to explicitly describe the lived experience. They agreed that since the total individual was explored it was a good method for researching subjects of interest to nursing practice, education and administration.

Phenomenology has become more popular among nursing researchers since it is a way to study "a lived experience" (Wimpenny and Gass, 2000). However, the use of phenomenology in nursing was criticized by Crotty (1996) who believed that there was a lack of relationship between the original philosophy and the new philosophy and May (1991) agreed by calling attention to "method slurring". These qualities created a lack of rigour and, thus, were not as respected as much among some scientists (Wimpenny and Gass, 2000).

There are various steps to phenomenological studies, but not all of them are needed to be adopted according to Spiegelberg (1984). Dempsey and Dempsey (2000) described the most commonly used steps as descriptive or eidetic phenomenology, phenomenology of essences, reductive phenomenology and the hermeneutic (interpretive) method. The hermeneutic method is conducted by interpreting the experience through the participant's experience in the light of socio-historical influences. This study adopted the eidetic, or descriptive, method which used the researcher as a tool after "bracketing" occurred (Dempsey and Dempsey, 2000; Wimpenny and Gass, 2000). However, the supporters of the hermeneutic method disagree with the need for "bracketing" since they believe that the subjective judgement of the researcher is important to phenomenology (Polit and Hungler, 1991; Wimpenny and Gass, 2000).

Eidetic or descriptive phenomenology consisted of the three steps of intuiting, analysing and describing (Dempsey and Dempsey, 2000). In intuiting, this researcher became the tool and listened to the participant's description during the interview, without criticism, evaluation or opinion. Analysis was done when the researcher repeatedly reviewed the data and identified the essences or themes of the experience based on the data. The third step was phenomenological describing. An attempt was made so that all critical elements or themes were described in such a way so that the researcher was able to communicate the meanings of the lived experience.

Phenomenology was conducted through the use of interviews. For this to be accomplished, the researcher had to have adequate experience and fluency with words, communication skills and listening skills in order to facilitate the interview and the collection of data, and the participants needed to feel comfortable enough to share their experiences (Streubert and Carpenter, 1999). The interviews were not to explain, predict or generate theory, they were for the sole purpose of understanding the participants' vivid descriptions of their lived experiences. Sorrell and Redmond (1995) pointed out that listening was thought to be as important as the narrative since the researcher was the tool. This placed a great responsibility upon the researcher to properly tell the narrative in such a way as to obtain all the richness and context of the experience.

However, this was not in agreement with Seidman (1991) who described the interviewer's interest in the participant's story as the basic requirement and the interview as a three-stage process. The stages were introducing the context of the participant's experience, the development of the experience and the reflection of its meaning.

A positivist paradigm was also chosen because it was considered a "strong" research method and used deductive reasoning (Streubert and Carpenter, 1999). It produced numbers which made it more of a scientific, or a "hard" research method. This paradigm placed value on rationality, objectivity, prediction and control.

The positivistic paradigm was based on its own set of philosophical assumptions concerning the world. These five assumptions, according to Dempsey and Dempsey (2000), were ontologic, epistemologic, axiologic, rhetorical and methodologic. These five assumptions differed from the naturalistic paradigm that was described earlier. In the positivistic paradigm, the ontologic assumption was that reality existed and could be broken down into components and studied separately. The epistemologic assumption suggested that the researcher did not influence the findings and was independent from the topic being researched. The axiologic assumption was that objectivity was of importance. Rhetorical assumption of this paradigm was characterised by the researcher writing in a formal style and using quantitative terminology to present 'results'. Within this paradigm the study definitions and hypothesis were stated at the start of the investigation. The methodological assumption, the process of the research, used a deductive reasoning process.

It was based on a fixed design, which focused on concepts isolated before the research. It produced mainly quantitative information, which were numerical data that had been analysed using statistical procedures and techniques. These assumptions were important in this study in order to investigate the perceptions of a larger sample of parents and nurses in a more scientific manner in order to add to the nursing body of knowledge (Burns and Grove, 1997). Abrams and Scagg (1996) suggested researchers carrying out quantitative research were interested in describing the data and then on inferring the effect of an intervention on the population of the sample, thus trying to produce generalisable results.

According to Brockopp and Hastings-Tolsma (1995), quantitative approaches have increased the nursing body of knowledge even though there have been problems associated with this approach. However, it was believed that the positivist paradigm alone would not allow the researcher to capture the human phenomena of those actually living the experiences that were studied. This could be accomplished by using the naturalistic paradigm mentioned earlier.

There were limitations to both types of research methods, the quantitative method having a strong internal validity but a questionable or limited external validity and the qualitative method having a strong external validity but a questionable internal validity. Dempsey and

Dempsey (2000) mentioned other limitations to both methods. They pointed out that the quantitative method of research offered data that, because it was reduced to numbers, did not answer nurses' questions about the health and illness experiences and was not useful to the real world since it lacked descriptive richness. They went on to list the limitations of qualitative studies as being "soft" research, lacking rigor and being too subjective.

Before the details of the qualitative and quantitative studies are presented, the common elements of both studies will be discussed. Since both studies were carried out in the same setting using the same sample and the same ethical considerations were undertaken, they will be described together.

3.4. Settings of the Qualitative and the Quantitative Studies

Included in this study were Greek communities in the northwest region of the Peloponnese, which included two large cities and seven rural areas and villages. Initially, the Directors or Head Nurses at various Community Health Centers were approached. The researcher explained the aim of the study, that confidentiality would be maintained and then asked them for their participation by providing names of parents and nurses to participate in the study. They agreed but were careful of which parents they contacted since they did not want to offend the parents. They contacted nurses and parents and explained the aim of the study and that confidentiality would be maintained and they set up meetings for the researcher. These preliminary interactions were important to the study along with the actual interviews. The researcher travelled to various community health centres within these areas and visited the homes in these areas. Since this subject was an emotionally and ethically sensitive topic it was impossible for the researcher to approach parents and ask for their participation.

The participants were asked to be interviewed by appointment in their home or office, these parents did not fill out the questionnaire until after they were interviewed, this was done in order to avoid influencing the outcome of the interview. The setting of the participant's home was very important in order for the participants to feel comfortable enough to express their true feelings about a very private subject (Brockopp and Hastings-Tolsma, 1995). Some of the men preferred to be interviewed in their offices in the absence of their children. Those

interviews that took place in the parents' homes included the children being present in another room and the researcher was fortunate enough to meet them. This gave more meaning and understanding to the comments made by the parents.

To locate more parents, the names, times and locations of parent-support group meetings were sought. The researcher approached the presidents at these group meetings and asked for permission to meet the parents. It must be noted that sometimes the presidents refused and the researcher had to leave without meeting any parents. Most times the presidents were pleased about the study, welcomed the researcher and introduced the study to the parents who responded positively.

In seeking more parents, the researcher contacted schools for children with special needs. The same responses were found, some directors refused to talk to the parents about participating in the study, while others were very enthusiastic. They expressed their concern that some parents might be insulted if they were asked to participate. The person in charge first talked to the parents and gained their permission for the researcher to contact them and to set up appointments for the interviews, which were held in each parent's home. The researcher could not contact the parents without the directors' permission since there was no way to access the appropriate database without their assistance.

The setting for the nurses were the Community Health Centres, nursing conferences and at local nursing education facilities. The researcher explained the aim of the study, that confidentiality would be maintained and then asked them for their participation. They filled out the questionnaires and some were asked to be interviewed. The interviews took place at the above facilities in a private room followed by their filling out the questionnaire.

All participants, nurses and parents, agreed to be audiotape recorded. These interviews were a means of obtaining more detailed information than was possible through the use of the questionnaire. It also enabled parents and nurses to discuss subjects that they felt were important but may not have been included in the questionnaires.

3.5. Samples in the Qualitative and Quantitative Studies

Although Morse (1991) supported the use of methodological triangulation, she suggested that caution must be taken to maintain the validity of each method since the use of an inadequate or an inappropriate sample could be a problem. The sample of quantitative studies was usually large and randomly selected while the qualitative sample was usually small and selected on how well they represented the subject being studied. However, she maintained that the same sample group could be used for both parts by choosing the most articulate and interesting participants of the quantitative study for the qualitative part of the study, which was what this researcher did.

3.5.1. Parent Sample

The purposive sample included mothers and fathers who had cared for their children with a CHP or disability which had resulted in altered body image. This level of persons was included to provide their perceptions of the nurses' role in providing support, information, counselling and nursing rehabilitation to them and their children.

The parent sample of the quantitative study consisted of 103 parents, 30 of the most articulate and experienced parents of this group were chosen to participate in the qualitative study.

3.5.2. Nurse Sample

A purposive sample of community and hospital nurses were approached to participate in this study. The nurse sample of the quantitative study consisted of 83 nurses, 32 of those nurses were also asked to participate in the qualitative study by being interviewed, 30 responded positively yielding a 94% participation rate.

3.6. Inclusion Criteria

Parents were included whose children had a wide range of illnesses and types of disabilities. No emphasis was given to the children's diagnoses since the literature stated that irrespective of the cause of the chronic illness or disability, parents faced similar difficulties and had similar needs (Norris *et al.*, 1998; Perrin *et al.*, 1993).

The inclusion criteria for parents in this study was that they had to have a child with a chronic illness or disability. A chronic illness was defined as (a) a condition with a duration of greater than three months, (b) a stable or a progressive illness course (relatively normal lifespan expected) (c) required extra care in performing daily activities, and (d) one in need of interventions to prevent serious complications (Knafl *et al.*, 1996). Included in this study were children with disabilities which were defined as any loss of function resulting in altered body image.

Both parents of a child were desired, but it was not required. The parents were required to speak and read Greek, some parents requested the questionnaires to be filled out by the researcher. They did not explain why they wanted this but perhaps they had difficulties reading. Since their input was valuable to the results of this study, the researcher complied with their request.

The inclusion criteria for the nurses were that they needed to be at least a three-year diploma graduate or a four-year university graduate of nursing, working in the community or hospital setting. The nurses were required to speak and read Greek. They needed to have cared for a chronically ill or disabled child some time in their career.

3.7. Ethical Considerations

Permission to contact the nurses and parents was granted by the Directors of the Health Centres and they provided the names of the nurses and parents only after obtaining their permission to do so.

Before the researcher approached any participant, the introduction was made after a referral of a doctor, a director or a nurse. In some cases, friends and relatives suggested parents they knew who had children with chronic health problems. The first contact with each family was made through a third person and only after the participant had agreed was a meeting arranged.

A complete explanation of the research aims and objectives, procedures and possible outcomes was given to each participant before obtaining verbal consent that the participant

agreed to proceed with the interview or the survey. All participants, nurses and parents, were informed that all information would be kept confidential and disguised so that their identity could not be known to others. In this way they were free to criticize without fear of retaliation. As Marshall and Rossman (1995) suggested, investigating a sensitive subject required that the participants' needs should be considered and their identities protected. Data collection was marked without using their true names in a further effort to protect participants from being identified (Polit and Hungler, 1991). Participants were asked demographic information to allow the questionnaires and interviews to have more meaning. All participants gave their verbal consent to join the study after they were assured that anonymity and confidentiality would be maintained. The participants were reassured that the interview could be stopped whenever they wished to do so. The process of being interviewed concerning such an emotional subject appeared therapeutic for the parents by allowing them to give meaning to the events. However, it is possible that reliving painful memories could have reinforced feelings of inability to cope (Noyes, 1999). Now each study will be described separately since they differed from this point on.

Part I. The Qualitative Study

Dempsey and Dempsey (2000) and Streubert and Carpenter (999) suggested that the number of interviews should be determined as the study progresses and no new information is obtained since that is when the research has reached the "*saturation of data*". Thus, in qualitative studies, a smaller sample may even be more beneficial since the researcher was interested in examining the situation in depth from several points of view. However, Morse (1991) was not in agreement with continuing interviews only until saturation had occurred but she believed that if interviews continued after that point they reinforced the initial findings. This study collected data until no new themes emerged, and then continued interviews as Morse (1991) suggested in an attempt to determine if new themes would emerge and also as a means to confirm the findings of the initial interviews. A descriptive design was used since the researcher was interested in explaining what occurred in this special situation of interactions between nurses and parents of children with chronic health problems.

3.8. Data Collection

Interviews are the most utilized data collection method in qualitative research studies and the three types are the structured, semi-structured and unstructured as identified by Rogers and Bouey (1996). This study used the semi-structured interview approach, which was a guided interview since the researcher had prepared a group of questions. These guidelines allowed the researcher to develop the areas of inquiry of specific interest, during the interviews.

Morse (1991) recommended the semi-structured interviews as more suitable for exploring emotionally sensitive topics and for studying a topic that the participants were not used to discussing. The interviews were used in order to achieve a better understanding of the topic being studied. Thus, the use of face to face, semi-structured interviews was the research tool chosen for the qualitative part of the study. Both groups were interviewed concerning the same topics of interest in order to explore their perceptions.

Over a 24-month period, data were collected through a series of 30 in-depth, semi-structured, audio-taped interviews conducted in the parents' homes or offices. The 30 nurses' interviews were carried out within the professional setting. The interviews typically lasted 1 to 2 hours because the participants were so eager to tell their stories.

When the interviews were carried out, the introduction period consisted of setting up the audiocassette recorder and then asking the parent or parents to describe the medical history of their child. All parents appeared to feel confident in the interview until the researcher asked the first question, "How did you feel when you heard of your child's diagnosis?" In most cases the parents seemed to lose their confidence and cried which will be described later under "Findings". The nurses' interviews were conducted in the same manner but they were not so emotional.

In this qualitative research study, the researcher revealed personal thoughts and feelings about the topic by writing in a reflective journal and then by "bracketing" or in other words by putting those thoughts aside in order to avoid preconceived ideas. In this way, the researcher attempted not to lead the interviews and the analysis so that they would be participant led.

This method was carried out before the beginning of the study and throughout the study as recommended by Burns and Grove (1997).

3.9. Instrument

A list of questions was prepared covering all of the topics discussed in the questionnaire. This was done to ensure that the interviews covered the topics of the questionnaires but at the same time, participants were encouraged to introduce new topics that they felt were important.

The questions that were included in the nurses' interviews were reworded and used in the parents' interviews. In order to explore the nurses' understandings of the reality of the parents' lived experience it was important to include the parents' interviews in the study. If the nurses' perceived the parents' feelings correctly, this would indicate congruence between them in role expectation (King, 1981).

During the semi-structured interviews of the parents the following questions were asked:

1. How did you feel when you heard of your child's diagnosis?
2. What was your spouse's reaction to the diagnosis? What was the response of other family members and friends?
3. How has your child accepted his/her chronic condition? How has the community accepted your child?
4. Who, professional or non-professional, helped or supported you emotionally or offered information concerning your child's condition and nursing rehabilitation?
5. What type of support and nursing rehabilitation would have been useful? Whose role is it to offer this support and nursing rehabilitation?
6. Were nurses involved in your child's care? What is your opinion of further ways that they could have helped you?
7. What fears do you have when you think about your child? Whose role is it to help you in this area?
8. What plans were made for the future of your child? Have nurses helped you plan for your child's future? Is it their role?

The interview questions for the nurses were as follows:

1. How do you think the parents felt when they learned about their child's diagnosis?
2. How do you think the spouse, the in-laws, the neighbours reacted to the child's diagnosis?
3. How do you believe the child accepted his altered body image? How has the community accepted these children?
4. Do you feel these parents needed emotional support and information concerning their child's condition and nursing rehabilitation? Whose role was it to offer it?
5. What type of support and nursing rehabilitation do you feel these children and parents need? Whose role is it to offer this support and rehabilitation?
6. What fears do you think these parents have about the future? Whose role is it to talk with them about their fears?
7. What plans do these parents need to make for their child's future? Whose role is it to help them in planning for their child's future?

3.10. Content Validity

Data were coded, sorted and analysed concurrently with the ongoing data collection, and the final analytic framework was presented to selected participants for their validation.

3.11. Pilot Study

The first four parents and four nurses interviewed were considered a pilot study in order to determine if it was necessary to refine the interview technique and to receive feedback concerning the interview. No changes were made since a great amount of data were obtained.

3.12. Data Analysis

The interview data were transcribed and studied using a phenomenological analytic procedure. The data collection and analysis occurred simultaneously as the taped interviews were interpreted. The coding of data was done to assist in the identification and analysis of important themes as viewed from the nurses' and parents' perceptions found in the data. This process of analysis took a great deal of reviewing before conclusions were drawn and the findings reported as suggested by Dempsey and Dempsey (1996). In this eidetic phenomenological study the researcher used intuiting, which involved focusing all attention

and energy on the experience being studied (Burns and Groves, 1997). It required deep concentration and complete absorption within the data as suggested by Burns and Grove (1997). There were various stages of analysis of this data.

The three stages of data analysis undertaken were data display, data reduction and data interpretation as described by Miles and Huberman (1994). Data display was accomplished by transcribing each interview as soon as possible after it was completed. Transcribing each interview required a great deal of time.

Data reduction was accomplished by reducing the information into smaller units in order to identify trends and patterns. The starting point of the analysis was to try to understand what the respondent was saying, then the data were divided up into component parts. This was done while looking for commonalities across the data. After highlighting the key words and phrases, they were grouped together as a first step of data interpretation. Thus, the reduced data resulted in the development of themes. Identifying themes and the associations between them was the process of interpreting data. The data from one set of responses was grouped with the other sets of responses for similarities. Each response was examined and divided up into component parts and commonalities. Saturation of categories was reached when no new categories were identified. A subject that appeared two or more times with no contradictions, were classified as a theme and considered worth being included in the findings as recommended by Cormack (1996) and Miles and Huberman (1994).

After completing the data analysis, the researcher had the more difficult task of carefully examining, organizing and giving meaning to the results, and needed to identify the practical significance of the results. In the next step which was the difficult process of interpreting, abstract thinking was needed involving introspection, reasoning and intuition. In this step all the evidence either supporting or contradicting the validity of the results needed to be considered, which really was a critique of the inquiry. However, as difficult as it was, stating the flaws in the study was an important step towards building a body of knowledge that could serve as guideposts for future researchers (Burns and Groves, 1997; Dempsey and Dempsey, 1996). Since data interpretation was a subjective process, this researcher attempted not to

interpret beyond what the data indicated and to relate the conclusions to the purpose of this study.

As part of describing the data, all critical elements or essences related to the lived experience were classified and these essences were described in detail. Attempts were made to determine patterns in the data such as trends, themes, attitudes and needs of the participants. Next, the concepts found in the literature were identified. The relationship between the concepts was stated and an effort to explain the relationship between the concepts was carried out.

After each interview, the researcher transcribed all the data and formed categories with the emerging themes from the data collected. It was taken into consideration that a person being interviewed could be analysing what he or she was saying as described by Oka and Shaw (2000), but these parents appeared to be too emotional to be doing this. It was possible in the nurses' interviews since it was not such a highly emotional topic for them as it was for the parents. This parameter was taken into consideration when the data were analysed.

3.13. Validity and Reliability of the Qualitative Study

Dempsey and Dempsey (2000) defined validity as to how well the findings actually represent reality. In order to do this, they recommended checking every part of the data collection process to determine if the findings were compatible with other information available. In this way, verbal responses of the interviews were checked against the answers of the questionnaires. For example, if most parents reported on the questionnaires that they felt all nurses were helpful but in the interviews comments were made about not being helped by the nurses, then this would mean more investigation was needed. Mays and Pope (1995) suggested that the use of triangulation was a way of increasing validity since the subject was looked at from two different directions.

Reliability depended on how accurate the information was from the participants and Dempsey and Dempsey (2000) suggested that in order to prevent inaccurate information, the questions needed to be reworded differently to determine if the answers remained the same, which was done. A second concern for reliability was that the interviewer could be biased or careless which would diminish reliability of the study. A useful method to determine this was related

to the possibility of replicability of the study by giving enough documentation of the questions and answers so another researcher could go to the same setting and obtain similar responses.

Streubert and Carpenter (1999) discussed the importance of trustworthiness and maintained that the goal of rigour was to accurately represent the participants' experiences. The ability of the questions asked needed to touch on the participants lived experiences, along with the researcher "*bracketing*" prior feelings and knowledge in an attempt to produce a purer description of data. In order to ensure trustworthiness of the data analysis, it was suggested that the researcher return to each participant and check the description with them, this, however was argued against by Denzil and Lincoln (1994) as being unethical when a highly emotional topic being studied. Streubert and Carpenter (1999) suggested requesting negative descriptions as a way of establishing authenticity and trustworthiness of data. This gave the researcher the chance to compare and contrast data.

However, various authors used different terms to describe the process of rigour, Guba and Lincoln (1994) used the terms, credibility, dependability, confirmability, and transferability. Credibility was sought as described by returning the analysis to the participants for a recheck, as mentioned above. Dependability depended on if the results were credible. Confirmability was determined as Dempsey and Dempsey (2000) suggested by the audit trail. However, Morse (1991) argued that even with the first researcher's documentation, the second researcher might come to other conclusions. Transferability referred to the use of the study's findings to others in a similar situation and according to Lincoln and Guba (1985) and Sandelowski (1986) this responsibility rests with the potential users and not with the researcher. However, Byrnes (2001) disagreed with this.

Byrne (2001) used different terminology to indicate the findings as "plausible". They were credibility, trustworthiness, rigour and truth-value. In considering credibility, Byrne (2001) suggested the researcher should discuss her qualifications, experiences, perspectives and assumptions. A method of triangulation was also suggested to help validate results, which was one of the reasons it was used in this study. Transferability was desired so that the findings

could be applied to another context. Confirmability was achieved through the researcher's audit trail, which was in agreement with Dempsey and Dempsey (2000).

Phenomenologists can choose to use either the hermeneutic or interpretive method or the eidetic method for data analysis (Dempsey and Dempsey, 2000). The eidetic or descriptive method was used in this study in order to use the researcher's reflection and insight to describe the phenomena, after "*bracketing*" was carried out.

Content analysis was a method by which the investigator collected data and analysed the data (Seaman, 1987). After listening to the participant's audio taped reports, transcribing them and rereading them, significant statements were identified. These statements were written and filed in order to manage the large amount of data being collected. This information was needed later in identifying how statements and themes emerged in order to make the final description as comprehensible as possible (Streubert and Carpenter, 1999).

Content analysis was applied while studying the qualitative data since it was used with unstructured material (Burns and Groves, 1997). Based on Field and Morse's (1996) principles of content analysis, a 'latent' content analysis was chosen since it allowed the researcher to analyse the data in the form of descriptions of messages. Latent analysis used the review of sentences, passages, and paragraphs to identify the themes. Latent analysis identified and presented themes in various categories similar to those found in the literature review.

3.14. Presentation of Findings

A description of a few parents describing their family was presented. Since a case study was described by Dempsey and Dempsey (2000) as an intensive and in-depth investigation of a single unit of study, these descriptions did not qualify as case studies. Yet, these short but interesting descriptions allow the reader to compare their own experiences with those described, which creates parallels between the two and thus, according to Stake (1994), serve as an epistemological function by allowing the reader to learn from these actual situations. For this reason, highlights of the interviews were presented in short descriptions in order to

provide a clearer picture than could be accomplished with just the presentation of quotes of the interviews.

A concept was considered important and included in this study if three or more participants confirmed it, as suggested by Miles and Huberman (1994). Throughout the review of findings, the researcher used quotes from the interviewees in order to support the interpretation of the data. The researcher attempted to use a balance of quotes and text and to add adequate interpretation of these quotes. The quotes were shortened when necessary to make a specific point but longer quotes were included.

In an attempt to address issues of trustworthiness, the researcher was constantly aware of the need to maintain rigour in order to ensure the value of the findings as being credible, transferable and dependable. From the planning until the end of the study this was taken into consideration by employing as many strategies as possible that various researchers suggested. Those implemented were: Burns and Grove's (1997) along with Morse's (1991) suggestion of the use of a triangulation approach in order to look at the lived phenomenon from several perspectives, the parents and the nurses, and by using two different research methods. Byrne (2001) points out that it helps to validate the findings by using "thick description" along with a purposive sample which she claims add to transferability of the findings, thus these were incorporated in the study. Koch (1994) suggests the use of a decision trail which needs to "explicitly detail the reasons for the decisions" made in the methodology, analyzing and describing of the study. Thus, there is a short, but detailed description of the steps undertaken along with an abbreviated explanation of why these decisions were made. Most of these points are explained throughout the text in more detail. This decision trail as recommended in studies by Koch (1994), along with an example of an audit trail of one theme are presented in Appendix X.

Koch (1994) suggested ways to improve trustworthiness of a qualitative study and that although readers may not agree with the researcher's interpretations, they should be able to follow the way the researcher reached those interpretations. She refers to Guba and Lincoln (1989) and uses their terms of credibility, transferability and dependability as ways of judging

the trustworthiness of a study. Credibility, according to Koch (1994), is established when the researcher describes and interprets their experiences as researchers. Since self-awareness is important, a journal should be kept which includes the content and process of interactions along with changes and reasons for these changes. However, different criteria were discussed by Byrne (2001). She says that the researcher becomes more credible based on documenting her qualifications, experiences, perspectives and assumptions. Also, any personal connections with the topic of the study should be identified and there are numerous strategies that can be built into the study.

An example of a strategy that Byrne (2001) suggested was by conducting the interviews several times or by conducting prolonged interviews, which occurred in this study. Another strategy was the use of triangulation which was discussed previously as it was included in this study. “Member checking” was added as an additional way of maintaining credibility, this was also undertaken with no changes needing to be made according to the participants.

Transferability, and never generalizability, was the goal identified by Byrne (2001). She maintains this can be achieved by using thick descriptions and a purposive sampling, both of which were included within this study. Sufficient contextual information was provided in order to offer enough information for the research consumer to judge the appropriateness of applying these findings to other settings.

Dependability, as Koch names it, while Byrne (2001) uses the term confirmability, can be maintained by a decision trail in order to establish audit trail linkages. As is seen here, there are disagreements concerning the ways and terms used in evaluating qualitative research, but Byrne (2001) offers reassurance that as this type of research evolves so will the ways of evaluating it.

3.15. Limitations of the Qualitative Study

All studies have limitations over which the researcher has no control. These limitations to the qualitative study were that it was possible that bias was involved although an attempt was made to limit this by “bracketing”. The participants may have presented only the information

that they wanted the researcher to hear. Time was also a limitation since the study required a great deal of time and a deadline had been set. It was very difficult to delve deeper into the subject by asking more personal questions since it was a very emotional subject and the parents' rights had to be respected. Another limitations of this portion of the study was that an extensive literature review had been carried out prior to the interviews. Dempsey and Dempsey (2000) argue that an extensive literature review must be carried out after the interviews to prevent the researcher from introducing bias to the study. However Cormack (1996) points out that no researcher is an "empty vessel" and that some prior knowledge is important in order to have identified the topic originally.

Part II. Quantitative Study

3.16. Procedure of the quantitative study

The first step of this study was to conduct a review of the literature to identify what has already been done, to develop insights into reported research, reveal research strategies, and to serve as a guide in discussing the results of the study. An adequate breadth or number of topics were reviewed which included: chronic illness, body image, alterations in body image, disabilities in Greece, stigma, nursing rehabilitation, paediatric health problems, communication skills, counselling by nurses, experiences of parents' perceptions and their coping with children with altered body image due to medical or surgical problems, nurses' role in chronically ill or disabled children, definitions of disabilities, and Greek studies available on the above subjects. The depth of the literature review included a great number of quality sources as recommended by Burns and Grove (1997).

3.17. Research Tool of the Quantitative Study

A triangulation method was thought to be the best method in order to provide better rigour and to make up for the limitations of each method if used separately. To conduct this original research, questions had to be developed to be used as a suitable data collection instrument (Dempsey and Dempsey, 2000). The instrument needed to be capable of yielding reliable

data to answer the research questions. This tool was needed to provide valid data compatible with the data analysis type (Robertson, 1994).

The research tool used for the quantitative part of the study was a questionnaire (Appendix I). The questionnaire included the concepts identified through the literature review. To explore role congruence between role performance and role expectancy for the nurse and the parent, each one's perceptions needed to be identified. The parent and the nurse created their own world of reality according to each one's perception, which was not necessarily the same. The nurse's role must focus on the parent's perception of their child's health problems and their adapting abilities while incorporating resource interventions (King, 1981).

The questionnaire was given to every parent in order to obtain their perceptions of the nurses' role as they had experienced it and what they had expected the nurse's role to be while caring for their child. Although nurses were asked questions concerning their role performance and beliefs, parents' participation was important to determine if they were in agreement with that of the nurses, or if there was a role incongruence.

The questions asked of the nurses were rephrased and the questionnaire was given to the parents in an attempt to assess both samples' role understanding. It was important to explore what are parents' and nurses' perceptions of psychological aspects of care were.

3.18. Rational for questionnaire development

The literature review identified the important concepts that needed to be included in the questionnaires in order to fully cover the important points of interest to this study. The articles that presented the topics of interest were included in the literature review and incorporated into both questionnaires.

The authors, Bycroft (1995), Deusen (1993) Jamieson (1996), and Salter (1988) all discussed how difficult it is to accept changes in body image. Camfield *et al.* (2001), Carson and Heiber

(2001) , and Yan *et al.* (1991) discussed the level of self-esteem among chronically ill children. Thus, items 1, 3, 4, 8, and 26 of the questionnaire were developed based on the above authors' suggestions about body image alterations and self-esteem. The intention of these questions was to evaluate whether or not the nurses understood the additional care required, and whether or not the parents felt comfortable in caring for their children with or without help.

The authors, Dashiff (1993), Hainsworth *et al.* (1994), Hatton *et al.* (1995), and Kearney and Griffin were the basis for the items concerning chronic sorrow (items 2, 12, 25 and 30). These questions tried to identify the parents' feelings of sorrow and depression concerning their children's CHP. Item 12 dealt with whether or not their child's condition could have been prevented, which was an opportunity to evaluate if the parents felt guilt concerning their children's problems.

The parents' needs for psychological support were discussed by Almeida (1995), Canam (1993), Garwick *et al.* (1998), and Seidman and Kleine (1995) and were represented in the questionnaire with items 9, 10, 13, 21, 29 and 32. These questions were concerned with whether or not nurses offered support and encouragement, and if nurses had offered other treatments when one had failed. Item 21 questioned if nurses felt comfortable when talking about the child's diagnosis in an effort to provide insight into how these two groups perceived the role of the nurse in this situation.

The nurses' role of offering information was emphasised by Garwick *et al.* (1998), Hentinen and Kyngas (1998), Hewison (1995), King (1981), and Porter (1998), They all identified the three support systems as emotional, tangible and information. The parents' attitudes toward the role of the nurse concerning the offering of information was the basis for items 16, 22, 24 and 28. The items under information included a look at how both groups viewed the medical role, along with the nursing role as seen in questions 16, 22, as mentioned previously. Maguire and Parker (1998) defined the role of the nurse as to offer support for future losses and that the parents' feelings of fear and grief are normal. Nurses are expected to offer psychological support by offering informal verbal and written information. The main

literature dealing with this topic were studies conducted by Black-Monson (1999), Fitzpatrick (1999), Johnson (2000), and Meleski (2002) They identified the importance of the nurses' role in offering counselling skills.

Stigma was the basis for the development of items 6, 7, 14, 15, 17, 19 and 31 of the questionnaire. These questions were concerned with the parents' rights of disclosure, along with their opinions of special schools and parent support groups as suggested by the articles of Charmaz (1991), Goffman (1963), Hehir (2002), Joachim and Acorn (2000) and Northway (1998).

Nursing rehabilitation and its importance for these children and their families were included in items 5, 20, 23, 33, 34, 35 and 36. These items were suggested by the literature which included Gibbon (1995), Henderson *et al.* (1995) and Stuijbergen and Roger (1997). Nolan and Nolan (1990) discussed their study of the UK nurse's curricula found that too few courses concerning CHP existed. The Greek articles of Amvirazi (2004) and Vardakastanis and Chantzipetrou (2004) reported their disappointments in nursing rehabilitation, which also encouraged these questions to be developed.

The items 11, 18, and 27 were concerned with whether or not the nurse should provide hope and encouragement, past, present and future. If these parents needed to prepare for their children's futures were suggested by Kearney and Griffin (2001), Knafl *et al.* (1996), and Van Riper (1999).

Nurses' roles were discussed in most of the articles, describing the need for them to offer more support. It was interesting to include not only the nurse's role as based on society's development, but also the medical role. Parsons' (1951) structural functionalism viewpoint explained that values concerning any action within a role can be either "instrumental" or "expressive" which were very descriptive of both the nurse's and the doctor's roles. Items concerning this subject were 19, 20 and 21.

3.19. The Questionnaire

The term “content validity” of a questionnaire measured what the researcher wanted to determine and how accurate these findings were. Content validity, in other words, provided an indication that the answers of the questionnaire supported the topics that were being studied (Burns and Grove, 1997). The validity of the questionnaire was established with reference to the specific use for which the questionnaire was designed.

Content validation was carried out by thoroughly examining the questionnaire content so as to determine whether it covered a representative sample of the subject being measured. Content validity was built into the questionnaires from the onset by the choice of appropriate questions. A panel of experts was chosen to measure the content validity and reliability of the questionnaire. The group of experts in their scientific field were two community care nurses, one paediatric nurse, two professors of nursing and a paediatrician, who were asked to evaluate the questionnaire. Each was asked to evaluate every question using a grading scale of 1 to 4. The score of grade 4 was given to questions that were strongly related to the aim of the study, grade 3 was given to relevant questions, grade 2 was for slightly irrelevant questions and grade 1 for totally irrelevant questions (Rovinelli and Hambelthy, 1977).

The surveys, in their initial forms consisted of 40 questions each. After the application of the validation method, a few questions were rejected due to their low scoring of under grade 2. Finally, 36 questions with grade 3 and 4 formed the questionnaires. The average score for the six (6) evaluators was calculated for each question. The average score (grade) for each question fluctuated between $3,4 \pm 0,6$ to $3,9 \pm 0,2$.

It was very important to evaluate the interrater agreement among the six evaluators in order to evaluate how similar or not their judgement was for each question. Cohen’s coefficient of agreement (Cohen, 1960) was found to be $k=0.85$ ($\text{var}k=0.16$, $p<0.05$). This indicated a very strong and statistically significant interrater agreement.

Face validity was not validity in the technical sense. It referred not to what the questionnaire actually measured, but to what it appeared to measure. It pertained to whether the

questionnaire 'looked valid' to the examiner who answered it and to other technically untrained observers (Burns and Grove, 1997). Thus, it appeared valid to nurses and parents so they could easily comprehend what the questions meant and what the goal of the questionnaire was.

3.20. Validity and Reliability

Since the answers to questionnaires were based exclusively on the participant's self-reporting, it was very important to include two additional characteristics: reliability and validity.

'Reliability' referred to the consistency of the scores obtained by the same persons when they were re-examined with the same questionnaire on a different occasion or with different sets of equivalent items, or under other variable examining conditions. The concept of reliability was used to cover several aspects of answer consistency. Questionnaire reliability indicated the extent to which individual differences in answers are attributable to 'true' differences of the characteristics under consideration and the extent to which they were attributable to chance errors. Validity was concerned with whether a measure was really measuring what it was intended to measure (Burns and Grove, 1997).

The basic types of validity were:

1. *External validity* was concerned with whether a result can be applied generally to specific people, other populations and other places (Abramsson 1974; Anastasi and Urbina, 1976).
2. The *construct validity* of a questionnaire was the extent to which it measured a theoretical construct or trait. Each construct was developed to explain and organise observed response consistencies and it was derived from established interrelationships among behavioural measures. Construct validation required the gradual accumulation of information from a variety of sources. Any data that threw light on the nature of the trait under consideration and the conditions that affected its development and manifestations represented appropriate evidence for this validation (Abramsson 1974; Anastasi and Urbina, 1976).

3. *Internal validity* (internal consistency) involved the correlation of subgroups of items with each other or with the total (Abramsson 1974; Anastasi and Urbina, 1976). It also involved and measured the internal consistency of the answers given by the participants. The latter consideration of internal validity was tied together with reliability (O' Malley *et al.*, 1983).

The most usual types and tests used to measure reliability were: Test - Retest, Alternate Form, Split Half, Kuber-Richardson, and Alpha Coefficient (Cronbach 1951; Anastasi and Urbina, 1976). The most commonly used method for defining the reliability of questionnaire answers is the one used here, that of Alpha Coefficient (Cronbach's coefficient) (Cronbach 1951; Anastasi and Urbina, 1976).

The external validity was quite important, as the results of the analysis indicated, because of their great agreement with the Greek and international literature. The structural validity of the questionnaire was satisfactory, as indicated by the derivation of logically expected conclusions that were in agreement with the literature. The α coefficient for the parents' questionnaire ($\alpha = 0.69$) as well as for the nurses' questionnaire ($\alpha = 0.74$) showed good reliability. The detailed conclusions and their agreement with the results of other researchers' studies were presented in the discussion.

3.21. Pilot Study

The instrument was tested by 10 parents and 10 nurses who met the inclusion criteria but whose results were not included in the study. The pilot study was essential to test the feasibility of the method, identify problems, test the data collection tool for validity, reliability, sensitivity and objectivity, and for the researcher to gain experience in using the data collection tool (Robertson, 1994). A sample was chosen, informed consent was obtained after the participants were informed of the study and made aware that their results would not be used in the final analysis because they were testing the data collection instrument (Robertson, 1994). Attention was given to ensure that no questions were unanswered which would yield missing values. No problems were encountered, although a successful pilot test does not always guarantee the absence of problems during the conduct of the main investigation (Dempsey and Dempsey, 2000).

3.22. Data Analysis of Quantitative Study

Descriptive statistics was used to describe the findings of the study using frequency tables. Chi square (χ^2) with continuity correction (Yates correction) was used to determine the statistically significant differences between the parents' and the nurses' responses. When the expected value / frequency was under 5, the Fisher's exact test was used to provide a more accurate answer as suggested by Dawson-Saunders and Trapp (1994) and Siegel and Castellan (1988). Associations and differences between variables derived were assumed statistically significant when $p < 0.05$. The statistical software package SPSS version 10.0 for Windows was used.

In the descriptive analysis, important information was obtained by counting how many nurses agreed with how many parents. In order to compare their answers, the chi square test was used. Since the questionnaire for each group was identical, the "slightly agree" and the "agree" columns were added together to form the "yes" or "agree" column necessary for this test. The same was done to form the "disagree" columns, thus forming a two by two matrix in order to make the responses of both groups comparable. There were different numbers of participants in each group, nurses (N=83) and parents (N=103), thus percentages were used to make a clearer comparison.

3.23. Limitations of Quantitative Study

One limitation of this study was the relatively small samples which was due to the difficulties encountered in obtaining permission to approach the potential participants. Another limitation of the survey was the possibility that the parents and the nurses had not always been truthful when answering questions. However, there was always the possibility that the combination of children with such a wide variety of diagnoses could influence the outcome.

3.24. Summary

In this chapter the aim and the research questions were developed based on the previous chapter, the literature review. The various research methods were reviewed and the final decision was made to carry out a simultaneous cross method triangulation approach. The qualitative study was described including the data collection, the instrument and the data

analysis, along with its limitations. Following this was the presentations of the design of the quantitative study with the description of the questionnaire, its validity and reliability, data analysis and its limitations.

The qualitative portion of this study which includes the demographic descriptions of the two groups, along with the descriptions of a few families, and the themes that resulted from the interviews will be presented in the next chapter.

Chapter IV. Findings of the Qualitative Study

In the previous chapter the aim of the study and the research questions were identified. This was followed by a discussion of the various research methods available and the reasons why the final decisions were made. The settings, samples and ethical considerations were defined. The data collection, analysis and presentation of findings were discussed.

This chapter will be dealing with the presentation of the findings of the qualitative portion of the study. It will present the demographic description of both groups, a description of a few of the parents interviewed and then the themes that resulted from the parents' and nurses' interviews. Thirty parents and thirty nurses were interviewed during the period of January, 2003 until August, 2004.

4.1. Introduction

In this chapter, the findings, a better insight to the perceptions of their experiences of caring for a child with a CHP from the parents' and the nurses' interviews are presented. Initially, portions of some of the most interesting parent interviews are presented in order to provide a description of some of the obstacles these families had experienced. Since this study took place in Greece, the Greek culture needed to be emphasised in order to ensure a better understanding of the results. The emerging themes of the parents and the nurses will be presented.

4.1.1. Description of the sample of 30 parents that were interviewed

A brief description of the sample that participated in the qualitative part of the study is presented. From the 30 parents participating in this part of the study, 10 (33.3%) were men, while the other 20 (66.7%) were women. Most of the parents were between the ages of 41–50 years old (14 people, 46.7%). Twenty-eight people (93.3%) were married while the other 2 (6.7%) were divorced. The majority of the parents had 2 children (63.3%) and had primary level education (11 people, 36.7%) or were high school graduates (14 people, 46.7%). Five people were university graduates, one of them had also completed a post graduate degree. The distribution of the 30 parents according to their occupation was: 2 were unemployed, 3

were civil servants, 1 was a teacher, 4 were self employed, 3 worked in the private sector, 2 were nurses, 1 was a labourer, 2 were on pension and 12 were housewives (Appendix II).

The children in this study had a variety of diagnoses, one child with Down syndrome (3.3%), one child with haemophilia (3.3%), one child with Mediterranean anaemia (3.3%), and a child with renal failure (3.3%). There were two children with amputations due to accidents (6.6%). There were three children each with autism (10%), deafness (10%) and diabetes (10%). There were four children each with mental retardation (13.3%) and surgery for cancer (13.3%), while seven children had cerebral palsy (25.7%) (Appendix II).

A description of some of the parents' experiences will be presented using fictitious names to protect their confidentiality. It is impossible to present each family's experience even though each parent has a special and unique story, showing the love and strength of the Greek family. The researcher believes it is important to discuss these families in order to present some background and quotes from these parents. Later, the general themes gathered from all 30 interviews and those related to this investigation will be presented.

4.2. "...Planning a journey to Italy...but landing in Holland!..."

Mrs A, a 44-year-old businesswoman, mother of four, described how she had noticed that her third child, a boy, at the age of 6 months was not meeting developmental standards.

Mrs A said:

"I told our paediatrician that there was something unusual about Frank, but he insisted he was fine. At the time I had other children so I knew what to expect but Frank was not the same as the others. Finally, it became apparent that he was not physically normal, but he is mentally fine. We lived in a village where everyone knew each other, my sister-in-law insisted that due to the social stigma I should hide Frank in the house. She said this needed to be done since my other three children would suffer from the stigma involved. I could not resign myself, or Frank, to such a life, so I went against society and took Frank everywhere with our family. I risked public opinion by defying social stigma and took my son out into society in an effort to teach society how to accept a less than perfect child."

She has been very successful in her community and has appeared on radio and television programmes to support the rights of disabled children.

Mrs A continued:

“Later, when Frank was six, we heard about a wonderful rehabilitation centre in Athens and so I spent endless weekends travelling 5 hours to and 5 hours back from Athens where physiotherapy rehabilitation was accessible for Frank. This was a very exhausting and difficult time for us and for all of the family. But one of the advantages was that we met wonderful nurses there, I am sorry to say that most nurses we had met up until then did not know how to offer support and they were not well enough informed. But, at the Athens Centre, the nurses must have been better trained since they were so supportive and offered information and “tips” concerning Frank’s care. From then on I realized what nurses could do!!”

“It is unfortunate that not all parents have the opportunity of meeting such wonderful nurses. Also, while I waited for Frank to finish his therapy at the centre I met other parents, which was really nice since finally I could talk to someone who understood. Until then I had no one with whom to really share my true feelings. The problem was that if I spoke honestly with family members about my fears and disappointments, we all became more depressed, for example my mother would start to cry, so I decided not to upset her by discussing my true feelings. But, with these nurses and parents I could be myself without them judging me or without them starting crying! I knew that the other parents had the same feelings as I did. It was great just to say things out loud for a change and then I would go back to my normal routine!”

“I could go on and on since I have 17 years to tell you about! Although he is completely paralysed as you can see Frank’s cousin developed a way for Frank to use the computer by breathing through that tube since he cannot speak or use his hands. He has really become great at it but now we have other problems. He watches his brothers and sister live a normal life and he has expressed his anger towards us for allowing him to live in such a state! He gets very depressed.”

“What he needs now is to have a good friend to spend time with, and a job. If he had a job, he could feel the importance of responsibility and the joy of fulfilling a purpose, perhaps belonging somewhere. He might not feel as depressed as he does now. He does not want to leave the house for weeks.”

When his mother was asked how she felt when she was told of her son’s diagnosis she used a metaphor to explain the bittersweet feeling of her situation.

She said:

“It was the worst news! The doctor gave me little hope. Its like you are preparing to go on holiday to Italy, you get all the tourist books and read up on all the tourist attractions and you believe that you are prepared. But, when it comes time to land, the air-hostess announces that you are arriving in Holland and not Italy. Although you are disappointed that you are unable to go to Italy, soon you grow to love Holland, if you remember to enjoy the tulips!”

She mentioned with irony that the only time that the government ever approached her concerning her son was with the notification for him to appear for army duty.

“We were very upset when they sent us a draft notice so I wrote a personal letter to the Minister of Defence. In it I explained the atrocity of the government towards people like my son and asked for a written apology. My letter was answered by the Minister who used the excuse that the files had not been updated”

4.3. “I pray that he is not on crutches...”

Mrs B, a 28 year old mother, whose son, Andreas, has haemophilia.

Mrs B explained:

“I am lucky since our son has the mildest type of haemophilia. Andreas was two years old when we realized something was wrong, I think it was important that he was two years old before we knew he had a health problem since by that time we loved him so much. I wonder if when a child is born with an obvious problem do the parents love that child the same as a normal child? You see, according to my husband, the Greek

men marry when they decide they want children. I remembered when I told people I was getting married their reactions were to ask if I was pregnant! It is true that often brides are dressed in white gowns and have big church weddings when they are seven months pregnant!! There is no shame, on the contrary, it is seen as a positive sign that the guy will become a father. The bride's in-laws are usually the most pleased! What I want to say is that an abnormal child is really a big disappointment to the parents, but, also to the whole family. I have met many women whose husbands left them and their children since they could not cope with their children's illnesses."

"I belong to a haemophilia parent-group which really offers me support. I am lucky, there is one woman there who has three sons with haemophilia! Due to the bleeding in the joints with every injury, joint changes occur that decrease mobility for our children. There are two types of treatment, one type is treating the child with a prophylactic regime and the other type is by providing treatment when a bleeding episode occurs. I have a wonderful, supportive husband and he is the donor for the medication that our son receives on a prophylactic regime. This draws our family closer together, but I have to admit that I have guilt feelings since my son has inherited this genetic disease from me. Mothers pass it on only to sons, can you imagine how bad that makes me feel! One of my many fears is that due to the joint changes that occur with every bleed someday he won't be able to walk and he will become immobile, so I pray that he will not be on crutches when he is 18 years old!"

4.4. "We will always make sure Anne is in fashion..."

Mrs D and her husband have two children, their daughter Anne, 8 years old, is severely mentally retarded and has some physical disability due to complications during birth. Mrs D confessed that she was not always as positive as she is now:

"I am now adjusting to caring for Anne after all these years! My family had a terrible time with me because after the birth of our healthy son two years ago, I tried to commit suicide. It really turned out to be a good thing because someone had to give me some attention! I finally received help to find ways of dealing with my

situation and my disappointments. Until then everyone had thought I was doing well when really I was just pretending to be all right! After I tried to commit suicide I received psychiatric care which has helped me to feel comfortable and now thanks to my renewed faith in God, I am able to cope with our life.”

“I have a problem with the cost of getting Anne to the Rehabilitation Centre since we need to take five buses there and five buses back, a total of ten buses three times a week! Anne weighs too much now for me to handle her alone up and down the steps of ten buses, so I take a taxi which costs too much. The health centre wants us to attend the rehabilitation centre closer to home but the only good feature is that it is close. It does not offer the facilities that our daughter needs so why should we be forced to go there so the government can show that they offer centres within the smaller communities.”

“You see the bicycle over there? It belongs to Anne, even though she does not understand and will never ride it, we bought it for her. We will probably dye her hair and pierce Anne’s ears when she becomes a teenager!”, she explained.

4.5. “We treat her as normal...”

Mrs E, a mother of four children, is a 49 year old, highly educated woman of upper-middle social class standing. Mrs E’s daughter was diagnosed with diabetes mellitus at 18 months old. Her daughter, Alice, now 16, appeared to be a very active and energetic young girl.

Mrs E described her life:

“At the time the diagnosis was made, 14 years ago, my husband and I were so scared that we would not be able for 24 hours a day to cope with the management of such a serious and tedious condition. Our daughter was only eighteen-months old! Her care involved blood glucose monitoring, insulin administration, food restrictions and urine testing on an infant. I searched for all the information I could find in the library, this was before the Internet was available. I tackled the problem through improving my knowledge concerning her diet, insulin administration and all the areas of treatment required for my baby. I bought very expensive scales and took great pride in

measuring Alice's food. As Alice grew, I used to use tricks such as weighing her portion of pasta and then I would tie it in a clean net and boil it in the same pot along with the family's portions. When it was boiled, my mother or my husband could feed her since her portion had already been measured. Throughout the years, doctors sent mothers to me when their children were diagnosed with diabetes and I used to try and train them in measuring their children's food. I remember one mother who laughed at me and refused to take such care concerning her daughter's diet. The last I heard her daughter has been having a lot of complications with her diabetes, which makes me so angry because I remember that mother as having a very poor attitude concerning her child's health care needs."

"Our daughter is doing very well, she has a good rapport with her doctor. I worry because she increases her insulin dose when goes out with friends so that she can eat anything she wants. She has passed out a few times due to low blood sugar but she's a teenager and I can't convince her how dangerous it is. I don't worry more about her than our other three children who are healthy. There are worries involved in raising all children!"

This completes the family reports. A review of the common themes that emerged from the interviews with the 30 parents will follow.

4.6. Analysis of the findings from the parents' interviews

Theme 1. "We have had no support..."

A few parents that were approached and informed of this study responded, *"Where have you been?"* and *"This is the first time that anyone has asked me about my feelings."* These parents appeared to be relieved to find someone attentive and willing to listen to their experiences, an apparent cathartic communication process followed. Theory has often described the positive outcome of counselling, which was what the researcher felt was accomplished through these interactions. Creasia and Parker (1991) reported that counselling skills play a significant role in aiding people with problems. The problems cannot be solved

with the implementation of counselling skills, but they can help people with their adaptation to the problem.

When parents were asked about where they received support while caring for their child, the answers were very distressing. Many parents that participated in the interviews mentioned that they did not receive any support or information concerning the care of their child. One mother admitted,

“I was so alone and afraid that I tried to commit suicide!”

This was an extreme case but demonstrated the emotional experiences that these people were confronted with along with the problems of actually providing daily care and support for their child and other family members.

The majority of the parents interviewed mentioned:

“We had so many questions but nobody would answer them!”

“At first we didn’t know what questions to ask.”

“We were lucky when we found other parents to ask.”

Other mothers stated that health care professionals had not approached them to discuss their feelings and problems concerning the care of their child.

A few parents felt the nurses had offered support:

“The nurses were wonderful and showed us how to give insulin injections.”

In response to the question of who offered help, most parents angrily said,

“Nobody helped us, we helped ourselves!”

Theme 2. “No information was provided...”

“No information was provided...” and specifically, the lack of adequate written and verbal information and advice was reported by all participants.

Most parents in this study expressed the complaint that not enough information was offered and they had to search by themselves to find what literature was available concerning their child’s diagnosis.

Many of the parents mentioned:

“If we had been given the information in the beginning, the progress of my child would have started then. It would not have started two years later when we discovered a rehabilitation centre that could help us.”

“Not all of us found out early enough on how to help our child.”

“It took us ten years before we discovered a parent support group where we could discuss our common problems.”

Theme 3. “Upon hearing the diagnosis we felt ‘great sorrow’.”

All parents that participated in the interviews described their feelings upon hearing their child’s diagnosis using the phrase “μεγάλη στενοχώρια” (“megali stenohoria”), which is translated as “great sorrow” (Mandeson, 1999) and is considered a typical expression of situations of sorrow within the Greek culture.

The parents’ matter-of-fact attitudes changed when the researcher asked the question, “*What were your initial feelings when you received the diagnosis of your child’s condition?*”. All mothers and most fathers responded to this question in an overwhelming way. Most began sobbing and all replied how shocked they were and that the news brought them “*megali stenohoria*”, which translated means “*great sorrow*”. Each sobbed while trying to express their feelings. All parents appeared relieved to be asked this question, many mothers expressed the feeling that, “*No one has ever asked how my son’s disability has effected me!*” “*No one has understood my need to express my pain and sorrow.*” Another father watching his wife sob at this question, simply said, “*How do you think we felt? Very sad!*” During the interviews, when recalling their emotions, the parents were sobbing and remembering how they had felt when their child was diagnosed. This was clearly a sign of the profound emotional effect each child’s condition had on his parents. Some parents stated that after the initial shock they sat down as a couple and made plans to make their child’s condition their number one priority and to do everything possible to improve his condition and then they proceeded from there.

The researcher asked the parents how their partners felt. All of the participants explained that their partners were very devastated with the news but some partners tried to find positive points to help offer support to the other parent. One mother recalled that her husband was very positive and promised that they would find a solution, but then she caught him crying. This was a very upsetting event for her since he had tried to reassure her that things were not so bad. When she saw him so distraught she says she realized the severity of the situation. She was used to seeing him as such a strong character. A similar story was told by many mothers.

All of these parents expressed their pain that their child did not lead a normal life, which made them feel cheated. Although the parents appeared to have made the necessary adjustments, in private they still mourned their child's chance for a normal life, as one mother pointed out, "*She can't even ride a bike or go to parties!*" Their grieving was more complicated because these parents felt an ongoing and open-ended loss. They have tried to assist their children in accepting their limitations and have helped them to carry out their daily activities of living. They felt that they had helped their children to adjust to relating to those around them.

However, many families described "*normalisation*" as a way of adapting to their situation. Parents understood that their child's illness was not normal, but they said that they insisted on the way they manage their child's illness and their family life as being normal. An example of normalisation was seen with a nurse mother of an autistic boy, one of her three children. She denies his autism and says, "*he just can't speak...we have a normal life style*".

Although very upset by the diagnoses, each parent felt relieved to find something could be done to help their child once the diagnosis was made. Many admitted that their next reaction was to try to find someone to blame. They questioned whether or not anyone in their family had ever had the same health problem. A few parents expressed their feelings of guilt, a normal reaction since some children had inherited the diseases from their parents such as haemophilia and Down syndrome. They expressed their wish for reassurance that they were

not the cause, the parents of the diabetic children repeated many times that *“diabetes was never in my family before!”*

Another mother told how the old women of the village had warned her during her pregnancy what precautions she should take:

“When I was pregnant I was not allowed to go to my aunt’s funeral since looking at a corpse would produce a deformed infant. They also told me that my child would be “marked” if I wanted a certain food and did not get it. I was not allowed to raise my hands above my head or my baby would be strangled by the umbilical cord.”

When they were informed that it was a custom for health visitors to visit the homes in the UK, all parents agreed that they could have used a health visitor, especially in the beginning when their children were diagnosed. They explained that everyday brought a new situation with new questions and new fears. If they had known that a health visitor would visit them, it would have given them more courage and reassurance.

Theme 4. “Our faith helps us....”

During the interviews most parents described their faith in their religion and their ways of carrying out their faith. The parents in the study often mentioned how they prayed for help for their children. They emphasised that they demonstrate their Greek Orthodox religion through worshipping icons, which are paintings of saints, the Virgin Mary or Christ. These parents respected the saints’ sacred connection to the spiritual world, and to ensure their family’s safety and health they performed a daily kissing of the blessed icons while making the sign of the Greek Orthodox cross.

Another mother explained,

*“Faith is very important and I pray often for my child to regain her health. It can happen, I have heard of it many times. I make promises or *tamas* to the Virgin Mary that if she makes my daughter well I will crawl on my knees for 2 kilometers before going into the church and lighting a candle to demonstrate my gratitude.”*

Several parents mentioned how they had traveled to different islands where there were churches that offered miracles, such as the island of Tinos. They went there to “bargain” with

the Virgin Mary to restore health to their children. Purnell and Paulanka (1998) described this as an example of the Greek culture's persistence in hoping for a miracle.

Some comments were,

"We believe in miracles!"

"According to our child's illness we chose which saint to pray to."

"We keep an icon above Jenny's bed to protect her."

Another mother reported,

"I finally received help to find ways of dealing with my situation and my disappointments. Until then everyone had thought I was doing well when really I was just pretending to be all right! After I tried to commit suicide I received psychiatric care which has helped me to feel comfortable and now thanks to my renewed faith in God, I am able to cope with our life."

Another mother, as reported earlier, commented,

"One of my many fears is that due to the joint changes that occur with every bleed someday he won't be able to walk and he will become immobile, so I pray that he will not be on crutches when he is 18 years old!"

Several parents mentioned that their in-laws had accused them of causing their child's CHP, they suggested that the illness or disability was because the parents were being punished for some evil act. According to Purnell and Paulanka (1998), this was not unusual since Greeks often saw illness as outside of their control and considered it was caused by either God, the devil, spirits or the envy of others. Many believed that God punished the non-religious with illnesses or that the "evil eye" could be the cause. Others believed the child's illness was from the parents ignoring their families, ignoring educational work, not respecting parents or staying out too late.

All parents described episodes of rejections either from family members or others, but the majority stated that they coped with this by maintaining their religious faith. When asked what would help them the most, many parents answered that public acceptance of their child

was most important. An experience shared by all the mothers that were interviewed was that there were many times when a neighbour, a family member, even a nurse or another child had made negative comments concerning their child's condition, which reflected the social stigma within the Greek culture. The mother of a 6-year-old girl with mental and physical retardation explained how devastated she felt by a family member's comment, *"it would have been better if she had not been born."*

Another example of the lack of social awareness on the part of the general public was presented by a mother when she mentioned that while travelling by ferry boat to a monastery with her 2-year-old boy suffering from leukaemia, a little girl approached her son in order to play with him. The girl's mother pulled her away, saying *"Stay away, can't you see he is sick, you might get it too!"* Many mothers told similar stories and that even their extended family members had made negative comments concerning their child's health problems.

Mrs M, a mother of a 10-year-old girl with mental retardation and physical spasticity, owned and managed a shop in a tourist area. In the summer, she has her daughter in the wheelchair next to her outside on the sidewalk.

Mrs M commented,

"My faith helps me otherwise I am so upset with Greeks and their attitude toward my daughter! The foreign tourists treat her so lovingly and friendly while the Greek customers ignore her or give her unpleasant looks. It is time that Greeks become more like Europeans. They need to become better informed concerning special needs children."

She continued,

"In Greece it is very difficult to take children with obvious health problems out in public since the general public is not sensitive to the needs of these children and their families. Strangers do not understand that by gawking and pointing they create an embarrassing situation for these children and their families. They are not aware that these people have the same needs as they do."

She went on to explain,

“I see the Greek society as a loving, family oriented society, but children who have obvious health problems are kept at home and are not generally seen in public. One of the reasons that these children are not seen in public is to avoid social stigma to the family, while another one could be due to the poor facilities available, such as inaccessible sidewalks. We have sidewalks but they are too narrow, obstructed by trees, lack ramps or they are usually taken up by parked motorcycles and cars. Then there are construction sites which use the sidewalks to store their supplies of sand and bricks. It is difficult to find a sidewalk to wheel a baby carriage let alone a wheelchair. Just recently parking lots at shopping centres offer handicapped parking which is usually taken up by non- handicapped people who I hope park there because they are not aware that the spot is reserved for the handicapped. I think it is the unawareness of the public which creates these problems for my child and for the other children.”

Social isolation was a fear and a major problem which explained the resistance of parents of deaf children to sending their children to a school for the deaf. They insisted on their children taking part in the public school with normal hearing children. Other parents expressed the feelings that the isolation of their child upset them more than anything else. They said how much they loved their child and enjoyed their child. They were saddened when they saw how others did not share their love of their child. Many parents expressed how strangers looked at their child in disgust and it upset them that their beloved child could create such a reaction from others. This was described by parents as one of their most painful situations. If the public loved and accepted these children, it would be a big relief to their families. A small example of public acceptance was seen with some of the children who were raised for many years in the small villages since they appear to have become a part of the village and were more loved and respected by the community.

Sometimes there were differences in the responses in this study of the parents, which could be due to the wide variety of health problems that were included. Westbrook, Legge and Pennay (1993) maintained that according to the Greek culture, different groups of illnesses received different degrees of stigmatisation. The less stigmatised were persons with physical

illnesses such as asthma, diabetes and arthritis, which were not usually apparent to the public. The persons more stigmatised were people with noticeable altered body image, such as cerebral palsy and paralysis. Persons and their families suffering from mental retardation, mental illness and HIV were even less accepted.

Theme 5. "We have many fears for the future..."

Many parents pointed out that besides the normal worries associated with childcare there were additional duties and fears depending on the illness or disability of the child. For example, one young couple, both nurses, had two children. Last year their 2-year-old son was diagnosed with diabetes. These parents expressed their many fears associated with getting their son to comply with the therapeutic regime.

"We are afraid he won't eat enough."

"We are afraid he will get too much or too little insulin."

"We are afraid he will sneak food from his sister."

Other fears they mentioned were of complications, that something would happen while they were sleeping, and that of leaving him even with a family member. They mentioned the usual fears for the future as 'how would he manage at school?', 'would he learn how to give the insulin himself?', 'would he have complications?', 'would he become employed as an adult?' just to mention a few. At present they have difficulties when he refuses to eat and they have problems with his insulin regulation. They described trying to perform a finger stick as a terrible scene with the neighbors believing that they were torturing the boy.

They went on to describe the difficulty in managing their daily program while caring for their son.

"We have trouble keeping up with his daily care, since we both work at the hospital as nurses, so we have to work opposite shifts. Under Greek law, as parents of a child with a CHP we are permitted to work 6- hour shifts instead of the usual 7½- hours. In this way one of us is able to return home in time to relieve the other one staying with the child. At least this has helped to relieve the fear of leaving our son alone with strangers or other family members. My husband shares the duties with me and

spends many hours “surfing” the Internet in order to find information to help us in raising our son. We have difficulty going out socially since our parents are unable to provide the care needed and sitters cannot be trusted.”

Thus, the couple has many fears, which have completely changed their life style in the last year and has made them feel very isolated.

The parents that were interviewed expressed many fears, the most common one was:

“What will become of my child if I die before him?”

They feared that if they died first then their ill child would become a burden to their normal child,

“My son will have to look after her all of his life.”

“ He will have to work in order to provide for his brother.”

Unfortunate children without siblings faced the possibility of being placed in an institution when their parents die, one mother sadly reported,

“We have no other children and we were old when we had George. We are afraid he will have to go to an institution when we die! What else can we do!”.

This prospect was a very distressing thought to the parents that were interviewed. Many parents were in the process of organising societies that would provide homes for their children with live-in health professionals in order to guarantee their child a future home. However, after discussing it for a while, they admitted that the funding was not available and that the progress was slow.

Other fears that were mentioned included the fear of their child’s health condition, prognosis, treatments, whether or not their child will suffer, and an additional fear that was unexpected was their fear of surgery. One mother whose daughter had hydrocephalus and required her third surgery, explained,

“I dread her having to go for surgery again. During the other two operations she suffered because she was so afraid and could not understand why I was not with her.”

This fear was also expressed by parents of children with autism and Down syndrome. One father explained,

“Since my son is unable to understand and to communicate, we dread this situation since where he would be with strangers and unaware of what to expect.”

This fear was an important finding in this study since it appeared that it was not a common finding in the literature.

One mother suggested a possible nursing intervention.

“A nurse from the operating theatre could meet my child several times before her surgery, I could explain to Maria that the nurse would come to her room in the morning and stay with her until she returns to me. Then the nurse would accompany Maria to the operating room and look after her and hold her hand until she was asleep. Of course as soon as Maria is asleep the nurse would be free for other duties until Maria wakes up. It is important for Maria that when she first opens her eyes she sees the same nurse so she feels that she is safe! But, the nurse must not wear a white uniform since Maria is afraid of anyone in a white uniform because of her past hospital experiences!”

Theme 6. “...it could have been prevented!...”

Another unexpected finding noted in this portion of the study was that many parents reported that their child’s CHP could have been prevented. Some mother explained,

“I could have had an amniocenteses, but I could never have had the abortion.”

“We were not genetically tested before I conceived.”

“If my husband had been more careful driving, we would not have had the accident.”

“I believe I was in labour too long.”

“If I had known I was pregnant I would not have taken the medication.”

One older mother explained,

“I had measles twenty years ago during the first trimester of my pregnancy and had an amniocentesis. The doctor warned my husband and I that the baby would have some deformity and advised me to have an abortion. Abortions at that time were used as a form of birth control. My sister-in-law has two children and has had three abortions! My husband and I discussed the possibility of abortion, but we could not go through with it. Now, we are so glad we didn't. Our daughter, Jenny was born partially deaf, and we had problems when she was to start school since we were encouraged to send her to the wonderful school for the deaf we have in our town. We sent her for a short time but then found private teachers to help prepare her to attend regular schools. She's a very bright girl and needed the competition of regular school. Finally, Jenny attended regular schools and she is now at the university studying to become a teacher for the deaf. We have loved and enjoyed her so much! When you asked to visit us, I wrote a short description of our life with Jenny in case you want to include it in your study.”

Theme 7. “Rehabilitation is most important...”

Many parents reported that rehabilitation plans were too often made according to the illness and disability and that the goals were not individualised enough for their child. An example of this was Tommy's mother

“The doctors insisted on Tommy going to deaf school and that he should learn to sign. This was not our goal. We wanted Tommy to learn to speak and not to depend on signing since this would limit his life. We live in a little Greek village where he would not have anyone to sign with and we knew he would be better off in a regular school. By attending normal school he will be better prepared to find a job and to earn a decent living.”

However, according to these parents, the doctors disagreed and described the parents as being in “denial”. The mother continued,

“Tommy attended the school for the deaf, and we discussed the matter with a nurse there. She secretly agreed with us and told us to continue with the school and the

signing lessons until she would tell us when Tommy could be transferred to the local public school. This is what happened and Tommy has attended public school with two hearing aids and he speaks!”

When this researcher visited his home, he greeted her and spoke, not too clearly, but it was a better means of communication than signing. He was a friendly child, full of enthusiasm. His parents had discussed Tommy’s potential and they felt he could handle a trade of some sort. Their goals were more realistic than the doctors. In reality, the nurse at the school for the deaf was acting as a “rehabilitation nurse” by listening to the parents’ goals and counselling them on ways of achieving their goals. The family felt she played a very important role in caring for their son.

Based on what this mother said, it might appear that rehabilitation nursing was sometimes being done but was not given the credit it deserved. It included the diagnosis and treatment of human responses that occurred to individuals with health problems that altered their body image and function. One father commented,

“Our son’s condition will never improve, yet the doctors and therapists set goals which are not achievable. This has caused many disappointments for us and our child.”

Some families interviewed complained that the health care professionals expected too much improvement and the disabled child, due to his condition, could not always meet these goals. Another mother suggested,

“Nurses should set small goals depending on my child’s actual condition and abilities, which would achieve a sense of progress instead of disappointment. In this way the illness would not be the centre of attention but my child’s’ needs would be.”

Among some of the parents who mentioned a conflict of goals with medical staff were the Greek Orthodox priest and his wife. This older couple have five children ranging in ages from 9 to 18 years-old. The priest explained,

“About five years ago, our eldest daughter, who was a normal thirteen- year-old, began to develop neurological signs such as inability to walk and talk. She began by

falling and her speech became slurred. She was seen by many physicians and it was finally determined that she has a very rare genetic disease. As you can see, she seems to hear us but can not talk clearly enough for us to understand her. We think it is even sadder for our other daughter, since she has been caring for her sister all these years, but now the same condition is causing her to be in a wheelchair and she can't talk either. We were living in the village but it was too difficult with two wheelchairs so we had to move into the city to be closer to better health facilities and we needed to have many ramps throughout the house."

"Health care professionals were setting goals based on current conditions while my girls' conditions continued to deteriorate. When the goals were not achieved we all became even more disappointed."

This was an example that showed that nurses and health care professionals' and parents' perceptions did not agree. These parents felt that in setting goals it was important to include the input of the family's information in order for nurses to assist in offering better understanding and care.

A few parents that were interviewed admitted that the family's well-being was not one of their goals since they focused only on the well-being of the ill child. This could have had an affect on the family structure, which could have caused some of the interviewed parents to divorce. The divorced couples had coped with their situation in various ways. One husband took custody of the 10-year-old autistic son while his wife raised their healthy 8-year-old daughter alone. Sometimes, these parents had to take into consideration the needs of the siblings. For instance, many mothers that were interviewed mentioned comments made by strangers when on trips, either for pleasure for the whole family, or for a specific health reason, such as "*Must you take the child on such a journey, can't you see he is ill?*" They explained that this was an example of how parents of healthy children did not understand that it was necessary for these parents to meet the needs of the other family members.

4.7. Analysis of findings from the nurses' interviews

4.7.1. Introduction

As previously mentioned, the nurse participants were found at Community Health Centres, nursing education institutes and nursing conferences. These interviews took much less time than those of the parents. Out of this convenient sample of nurses that participated in the quantitative part of the study, the 30 most experienced and articulate nurses were chosen, as advised by Morse (1991) and agreed to be interviewed. Altogether 32 nurses were approached since two nurses had refused, maintaining the level of participation at 97%.

4.7.2. Description of the sample of 30 nurses that were interviewed

A description of the sample of the nurses that participated in this part of the study is presented here.

Out of the 30 nurses participating only 2 (6.7%) were men and the remaining 28 (93.3%) were women. The majority of the nurses were between the ages of 26–40 years old (19 people, 63.3%). Fourteen nurses (46.7%) were married while another 13 (43.3%) were single. Only 2 nurses (6.7%) were divorced and 1 (1.2%) was a widow. The majority of the participants were divided between those who had 2 children (40%) and those with no children (43.3%), those with 3 children (10%), while the minority had only 1 child (6.7%). All participants were Greek Orthodox, 40% had completed 3-year hospital diploma schools. The other 60% of the population had entered nursing education by passing the Greek general university exams, 43.3% of these had completed the Technological Educational Institute, a 4-year polytechnic institute. The other 16.7% were university graduates. The purposeful sample was of 30 nurses who had completed 3 or 4 year nursing studies and who had at some time cared for a child with a chronic surgical, medical or genetic disease or disability. This criteria was established in order to maximize information about the central issues from a particular viewpoint as suggested by Patton (1990). The average length of professional experience was 11.27 ± 8.46 years, while the average time in the particular position was 8.47 ± 7.77 years (Appendix III).

Data collection was achieved through in-depth, semi-structured interviews in order to go beneath the surface to a deeper understanding of the nurses' thoughts and feelings, the same was done with the parents' interviews. The style of the interviews with the nurses was informal and conversational. In the beginning very broad questions were asked which became progressively more focused.

The themes that developed are presented here.

Nurses' Theme 1. "We don't discuss the diagnosis...we don't even change dressings!"

Nurses made remarks such as the following:

"In our department we are not allowed to read the patient's chart, not their history, their progress reports or their lab results! This shows the respect the doctors have for us!"

A nurse reported how she had offered proper information to parents and they had listened and thanked her. Later, she overheard the father say,

"That's only what the nurse says, let's go ask the doctor to be sure".

Other nurses commented:

"My colleague tries to act smart by telling the parents about various options, it's not really our job!"

"Nurses are not as educated as doctors, only some nurses might be qualified because they keep up with medicine!"

It appeared that some nurses felt that it was not their role and that the general public had little respect for nurses' opinions. They suggested that this further discouraged them from taking on the role of offering advice, information or support.

"I need to be trusted and my opinion respected in order for parents to ask me for my advice and information," reported one nurse.

Another nurse said,

“I do not neglect these parents, on the contrary, I feel empathy for them and I wish that I could help them. But, what can I do to help them?”

Other comments made were:

“Most parents will only listen to the doctor.”

“From my experience, I feel I have much to offer parents, but from the way they react I feel my hands are tied.....many are unapproachable by nurses.”

Some nurse participants strongly believed that the parents had a right to information relevant to their own situation. They perceived that parents had inadequate preparation for their child’s diagnosis in terms of receiving information and counselling support. They expressed their feeling that some parents were not well enough informed about prospective treatments and their effect on long-term outcomes and also about other options that were open to them. Nurses were quite vocal about this.

“Some parents were not told that there were special buses to take their children to school.”

“Jenny’s parents were not told that their health insurance would pay every two years for her hearing aid to be updated.”

Many participants realized that not all parents had access to a knowledgeable person to gain information. Not all parents took the initiative and sought information, some nurses suggested that the parents who were articulate and actively sought information gained knowledge.

Some nurses recognized the need for counselling skills during the difficult periods experienced by the parents such as diagnosis and age milestones.

“Parents need to be alone with a nurse so they can really express their fears and not upset their child. To prevent upsetting their child, the parents always try to appear happy in front of the child.”

Some nurses expressed their need to understand basic counselling since they were the ones seeing all parents, in order to be able to offer advice when possible or refer the more serious cases to a specialist. In this way the entire family could be included so the nurse could evaluate each member's acceptance of the disabled or ill child and the illness' influence on the family. They felt it was important to understand that other family members need information and psychological support.

A few nurses, believing that families could be supported through information-giving and counselling, suggested that they should act as advocates:

“Nurses, as advocates for the child and his parents, should inform the parents of their rights, making sure that they have all the necessary information to make informed decisions, supporting them in their decisions and protecting their interests.”

Another nurse was very upset and reported,

“Mrs G was not informed that after that procedure her daughter could get worse.”

Nurses may perpetuate the power relationship between medical and nursing staff, and doctors and parents. However, it was possible that nurses perceived a sense of powerlessness within the medically dominated hierarchy.

“I feel uncomfortable informing parents since the physicians acted like I was trying to be smart by doing their job!!”

This disempowerment of nurses led to disempowerment of parents which threatened the notion of parent advocacy and parent autonomy.

In this study, some nurses tried to help parents articulate for themselves, as one nurse offered this suggestion:

“I encourage parents to write down their questions before they meet with their physician since they tend to forget what they want to ask. In this way, I encourage them to question treatments and to open discussions on topics that are bothering them.”

This was a positive action since the parents felt they were assuming a better sense of control. The provision of information was perceived as the most important method of empowerment since it gave the parents a sense of control and relieved anxiety. The nurses in this study suggested that parent autonomy was compromised by their lack of knowledge, which made them feel powerless and frustrated.

Other comments made were:

“Sometimes I avoided the parents since they wanted to ask me questions and I didn’t know what to answer. I feel confident to discuss the more common illnesses like asthma and diabetes but then there are many rare illnesses that I do not know enough about.”

“I felt very uncomfortable when the parents ask me that if it was my child, would I agree to a certain treatment. What can I say, since I do not know all the pros and cons of the treatment? How could I answer them?”

“Often, I tried to stay away from parents that have children with conditions I did not know enough about. I am pleased to approach parents of children with diabetes since I am very informed about diabetes. I know I can offer a great deal of support and information about diabetes.”

Others reported problems with parents.

“In my experience, the parents are sometimes difficult to deal with and have an “attitude” when I try to care for their child.” one nurse reported.

“The parents want to remain in control and insist that they are the experts and that they know more than we do!”

In reality, the parents were usually better informed on ways of caring for their particular child while the nurse might know how to care better for the specific illness. These two aspects are not the same. The parents felt they were the more expert after having provided years of care for their child. Nurses sometimes complained about the families.

“The other family members are very insistent and too many of them visit at the same time, we are always asking them to leave and we often have to call security to go from room to room to get them to leave. But usually they hide in the back steps and slowly sneak back in.”

“The family worries too much and allows the child to scream when procedures are done! They want to stay with the child while we carry out procedures.”

Nurses' Theme 2. “Families don't want our advice.”

“They would think that I was over-stepping my boundaries.” “Sit and talk to parents! I could not do that since my colleagues would think I was trying to get out of work.”

Many nurses mentioned their lack of knowledge as a reason that reduced their communication with parents. Many nurses admitted to “looking busy” in order to prevent the parents from asking questions that they were not prepared to answer.

“I try to act busy so if I am asked something I don't know I pretend not to hear the question. What can I do? We have no education since we finish nursing school and there are so many diseases!”

However, there were nurses who wanted to communicate more with parents but felt colleagues would not understand.

"If I sit down to talk to the parents, my colleagues feel I am trying to get out of work. They don't understand how important it is for these parents to express themselves freely. Usually they act as if everything is fine for their child's sake, for their family's sake and thus, are never able to really express their fears. Even if I don't know the answers to all their questions, I feel I can ask around and get back to them later with correct information. But not all the nurses agree with me."

Thus, some of the nurses recognized the need for interpersonal and counselling skills, but felt that they were inadequately prepared to deal with the counselling role. Advocacy was considered by some nurses to be a moral and professional duty, the nurses explained that the parents were often too worried to ask questions and perceived doctors to be extremely busy and high authority figures.

When asked how they responded to the parents' fears that something was wrong before the diagnosis was made, there was a difference of opinion. Some nurses mentioned that they felt it helped the parents if they reassured them that everything was normal. Others mentioned that they never approached the parents in order to avoid giving the parents the opportunity to voice their fears. A few nurses expressed times when all they could do was sit and listen to these parents but felt they really could not offer any help to these parents. It appears that these nurses were unaware that this was a form of offering counselling skills. Others nurses interviewed felt that it was important to reassure the parents and explained that it would have been cruel to increase their fears before a true diagnosis was made. They expressed the ideas,

"...eventually the parents would learn that there is a problem"

"...they will have plenty of problems, so it is best for them not to start worrying before the diagnosis is made!"

Nurses responded with comments such as,

"...the doctor is responsible for offering information...",

"I would be considered to be interfering in the doctor's work...other health care professionals would think I was being 'smart'",

“Parents would not listen to me....”

Many nurses did not believe it was their place to try and offer information while others felt confident in doing so. Even after the parents knew the diagnosis, the nurses and the physicians felt that the news should be said in a fashion as lightly as possible in an effort not to increase emotions of distress and anxiety from the parents. Some nurses expressed that difficult days were ahead and felt giving too much information would increase the parents' stress if discussed at the time of diagnosis.

However, this was in contrast to many parents' statements that they would rather hear the truth of the diagnosis immediately no matter how bad the news. They felt that only then, being fully aware of the situation and the possible obstacles, would they be empowered to proceed to provide the best future care for their child. Many parents mentioned with remorse that they had *“lost valuable time at the beginning of the diagnosis”* because they were not made aware of the situation as well as the resources that were available such as parent support groups, rehabilitation centres and alternative treatments. Thus, many parents did not agree with some of the nurses' opinions that time for the parents to adjust to the diagnosis was helpful. However, other parents expressed the opposite opinions, that they had feelings of distress and panic since too much information was provided and no emotional support was offered.

Some nurses interviewed were very empathetic and felt proud that they were carrying out their role in helping these parents. Others felt that only the physicians were the qualified health professionals to refer the parent to since it was felt that they had more current information. Many nurses felt uncomfortable with the parents since they had been taught not to interfere with what the doctor wanted to tell the parents. They expressed their fears of overstepping their boundary.

Nurses' Theme 3. "Parents don't mourn...their child didn't die."

When nurses in the study were asked to describe how they thought the parents felt at the time of diagnosis many used the phrases "*very shocked*", "*very depressed*" and "*megali stenahoria*" (great sorrow).

Many nurses expressed similar opinions that they felt that families over the months and years adjusted as they become confident in caring for their child. When asked if they felt the family was suffering from grief over their child's body image alterations many answered that feelings of anxiety, worry and adjustment were experienced by the parents during the first few months after diagnosis. Other nurses mentioned that in time many families adjust to the problems and proceed with life. When the nurses were asked if they think the parents were mourning the perfect child they lost, many disagreed with this and mentioned that in time the parents adjust.

Nurses described the parents' experiencing a period of psychological trauma and suffering which extended from the beginning when the parents first became aware that their child had a health problem, through the diagnostic period and into the treatment phase. The nurses gave examples from their own experiences of strategies that parents adopted in order to appear to be coping but eventually the parents had to abandon them.

One nurse reported:

"Mrs D seemed so happy and adjusting to her son's illness until I began to discuss his future and she broke down and was absolutely distraught and began crying."

Many nurses understood that the parents felt threatened by their child's condition and these nurses expressed their feelings that they regretted their own lack of formal counselling skills and experience in dealing with such sensitive issues. These nurses empathized with these parents by stating that they identified with these parents by imagining themselves in the same predicament.

Nurses' Theme 4 "...The parents don't register their children...social stigma."

Some nurses reported that most parents refuse to register their children at the local health centres because they did not wish to call attention to their child's limitations. As one nurse explained:

“There is a traditional belief that disability runs in a family or is a punishment by God, thus, the parents fear that their other children will not find suitable ‘mates’ when they grow older. Parents and other family members fear losing work and social status if their child’s condition becomes widely known.”

Many nurses expressed their belief that social stigma and social isolation were very well known within the Greek society. However, a few older nurses expressed their opinions that,

“Things are much better today. There is not so much shame as it was years ago”.

In other words, they felt that social stigma was not as strong today as it used to be.

Nurses’ Theme 5 “...many parents fear that they will die before their child...”

Some nurses told about mothers and older fathers who expressed their fear that they would die before their children. Their fear concerned where would their child live if anything happened to them. The nurses explained that there were other questions that the parents had asked them such as:

“Will she continue to feed herself?”

“Will he still be able to walk?”

“Will he be bedridden?”

Another nurse was approached by the mother of a diabetic girl and asked if the girl would be able to marry and have children. The nurses explained that these were difficult questions to answer and that they had to refer the parents to the physicians.

Nurses’ Theme 6. “Rehabilitation is done by therapists...”

Most nurses felt that only speech and physiotherapists were responsible for the rehabilitation of these children. They expressed their belief that rehabilitation was very important and they seemed aware that it was their role to evaluate the adjustment of the child and his family.

A few nurses expressed their opinions that it was important not to try to console parents by telling them, as some parents claimed they had been told, to take care of the child for as long as they have him. However, other nurses claimed it was important not to spoil the child by neglecting to create proper long term planning for the child's future. As one nurse pointed out:

“Sometimes people encourage the parents to let nature take its course when really a plan should be made for the child's educational plans and social activities and for updating their equipment.”

However, another nurse commented:

“These children need more training so that they can be more independent. But in our society, it is difficult to explain to Greek parents that they should spend money to educate a disabled child, since they see it as a waste of money. One father refused to train his disabled daughter because he wanted her to stay home and help care for her younger brothers.”

Another nurse mentioned that there was bias in favour of male children more money was spent for their education. Although the girls were loved, this culture did not believe in spending the family's money to educate a disabled child.

4.8. Conclusions of Qualitative Findings

During the qualitative portion of this study, a few new topics emerged during the interviews that had not been included in the survey. The parents presented new issues concerning an additional fear that some parents expressed, such as their child having to undergo surgery in the future, and the majority of them did not expect or accept information from the nurses. The interviews with the nurses produced new information that they often felt too

embarrassed to carry out their roles and that they felt that parents did not want information from them.

This study demonstrated that many nurses in the sample group have been taught that having a child with a chronic illness or disability was a very stressful experience and it was suggested that some do not get beyond these old feelings in order to offer help to these families which Northway (1997) writes about. Some parents in this study voiced their disappointment with nurses since some nurses described them as maladaptive when they found joy in their children. Another reaction voiced by the nurses was that the parents were often “*in denial*” when they treated their child as “*normal*”.

“Nancy insisted her son was normal, poor girl.”

“The parents always look so sad...”

It must be pointed out that nursing researchers call this concept “*normalization*” as described by Deatrick *et al.* (1999).

A few parents expressed their feelings that they felt strengthened by their experience of caring for their child. In this study many parents expressed sorrow that their child could not attain certain goals expected of them but they also expressed joy and pleasure from their children. They made comments such as:

“She is so innocent...”

“Her smile is so genuine..”,

“When he reaches a goal we all celebrate...”

“Other parents cannot appreciate how wonderful it is to have such an innocent child.”

“We are lucky she is a good student.”

However, most parents felt it was a very difficult experience, and could have adapted better if they had been supported by a nurse’s home visit which did not exist as was verified by both samples.

This study's results suggested that nurses comprehended how difficult it was for these parents to fulfil these roles and tasks. Most nurses admitted that they did not offer counselling since they did not feel comfortable in allowing these parents to express their fears and feelings in a non-judgemental environment. Most nurses and parents seemed to agree that nurses had not prepared the parents for transition phases that they encountered. The parents suggested that they would have felt empowered by having knowledge of their child's prognosis. A few nurses expressed their feelings that greater skill in communication would call for a greater knowledge base and updating of information, which was not being offered at this time. While they realized that these actions were needed they continued to reflect that more interpersonal and counselling skills were needed to improve their communication with the parents.

Only a few nurses informed the parents that their experiences and feelings were expected and normal and thus, helped these parents to utilise their normalisation strategies. In addition a few nurses felt it was important to explain to the parents that their issues and feelings were not always the same as the child's.

Some mothers in this study, whose children were more severely impaired and functionally dependant, appeared to suffer much more sorrow and appeared to be in poorer mental and physical health. They complained that they had too many responsibilities and tasks to perform and that they received little emotional support from their family and friends.

It was interesting to note that a few fathers, upon hearing about their wives being interviewed, requested to be interviewed. The fact that fathers were willing to be interviewed was a contrast to a study done by this researcher, on the same topic, in 2000 when fathers refused to participate. This current study found the parents willing to be audio-taped and they expressed the hope that the results would be used to improve the opportunities offered to their children. This study did not generate new theory, however, important information was obtained that could be used to make recommendations for nursing practice, education and research.

The nurses believed that they had offered support and encouragement but they found out that information was not wanted by most parents. Other nurses mentioned that even though they should offer more information and support they were too hesitant to do so since colleagues ridiculed their efforts. Both nurses and parents were unaware of the nurse's role in offering nursing rehabilitation. Most considered rehabilitation to deal with physical or speech therapy. Both groups expressed the need of nursing rehabilitation to be adjusted to the child's needs and to concentrate more on the psychological needs than is being done at the present. Many parents strongly expressed the opinion that although they wanted support, encouragement and information concerning their child's diagnosis, as well as the proposal of the use of alternative treatment, they did not expect nor wish this type of support to be offered by nurses. This is an area which warrants further research to examine this phenomenon.

4.9. Summary

Based on the previous chapter, the qualitative portion of the study was carried out and this chapter provides a description of the sample of the parents and the nurses that were interviewed. A description of some of the parents' experiences were presented in order to provide rich description which adds to the trustworthiness of a study according to Streubert and Carpenter (1999). A review of the common themes that emerged from the parents' interviews then followed. Analysis from the findings from the nurses' interviews were included along with a description of the sample of the nurses that were interviewed. The themes were presented along with the conclusion of the findings.

In the next chapter the quantitative portion of the study will be presented, with the graphs of the descriptive analysis and the chi-square and Fisher's exact tests.

Chapter V. Findings of the Quantitative Study

In the previous chapter the findings of the qualitative portion of the study were presented. This chapter will include the findings in graphs of the quantitative portion of the study.

5.1. Description of the Parents' Sample

Out of the 103 parent participants, 34 (33%) were men and the other 69 (67%) were women. Most of the parents were between the ages of 40–50 years old (58 people, 56,3%). This sample included 94 people (91.3%) married, 7 (6.8%) were divorced and 2 (1.9%) were widowers. The majority (68%) of the participants of this study had 2 children (68%). The majority of the parents that participated in this study were Greek Orthodox (98.1%), one was Catholic and another parent refused to state his religious affiliation. Twenty-one people had completed only primary school level education (20.4%). The majority of the parents were high school graduates (57 people, 55.3%) and 25 were university graduates (Appendix IV).

The distribution of the 103 parents according to their profession was:

5 (4.9%) were unemployed, 10 (9.7%) were civil servants, 7 (6.8%) were teachers, 16 (15.5%) were self employed, 24 (23.3%) worked in the private sector, one (1.0%) was a social worker, 3 (2.9%) were nurses, 31 (30.1%) were housewives, 3 (2.9%) were labourers and 3 (2.9%) were pensioners (Appendix IV).

The distribution of the CHP of the children was:

4 (3.9%) with haemophilia, 7 (6.8%) with amputations, 5 (4.9%) with physical disabilities, 3 (2.9%) with asthma, 7 (6.8%) with autism, 13 (12.6%) were deaf, 6 (5.9%) had Down syndrome, 2 (1.9%) suffered with epilepsy, 3 (2.9%) had suffered a head injury resulting in disability, 3 (2.9%) had Mediterranean anemia, 2 (1.9%) had renal failure, 3 (2.9%) had mental and physical disability, 14 (13.6%) had mental retardation, 7(6.8%) had cancer, 15 (14.6%) had diabetes and 9 (8.7%) had cerebral palsy (Appendix IV).

5.2. Description of the Nurses' Sample

In this study, 83 nurses participated of whom only 6 (7.2%) were men and 77 (92.8%) were women. Most of the nurses were between the ages of 30–40 years old (49 people, 59.1%).

Married were 53 nurses (63.9%) and another 26 (31.3%) were single, only 3 (3.6%) nurses were divorced and 1 (1.2%) was a widow. The majority of nurses either had no children (31.3%) or had two children (34.9%). Eighty-two (82) of the nurses (98.8%) were of Greek Orthodox religion, while one refused to declare religious preference. The majority of the nurses were graduates of hospital diploma schools of three-year duration (47%), and 36.1% of the sample had completed four-year studies at the Technological Education Institute. Only 9 (10.8%) of the sample had university-nursing qualifications and 5 (6.0%) nurses had also completed postgraduate studies in the field of nursing. The average length of professional experience was 11.76 ± 6.74 years, while the number of years in a particular position was 9.07 ± 6.66 years (Appendix V).

The most significant responses to items (questions) are presented in the present chapter by figures, the remaining figures and tables illustrating the parents and the nurses responses can be found in Appendix VI, VII, and VIII.

5.3. King's Individual System

King's Individual System included the concepts of "self", "body image", "growth and development" and "time and space".

5.3.1. Self and Body Image

Item 1

Items that referred to the "self", such as item one, resulted in a non-statistically significant difference, ($p > 0.05$) based on the Fisher's exact test between the parents' and the nurses' responses. A large number of the sample of both parents (98%, $n=101$) and nurses (95.1%, $n=79$) agreed that it was more demanding to care for a child with CHP or disabilities than caring for a healthy child. With this question the nurses' responses illustrated that they understood the complex and difficult situation that these parents were in.

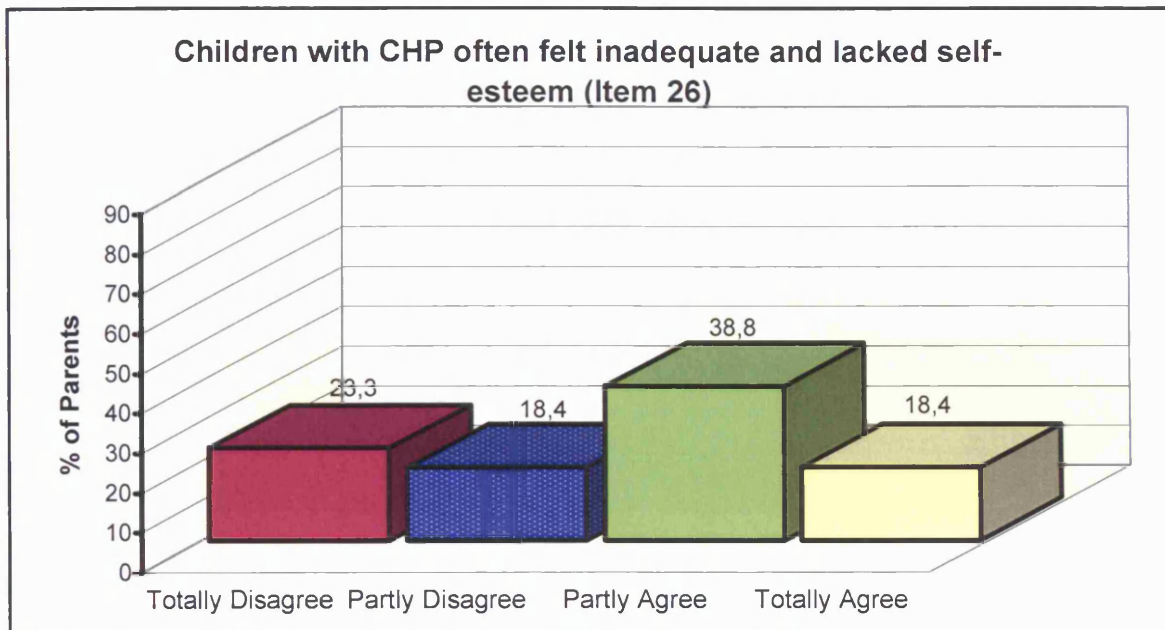


Figure 1. Parents' Responses - Children with CHP often felt inadequate and lacked self-esteem

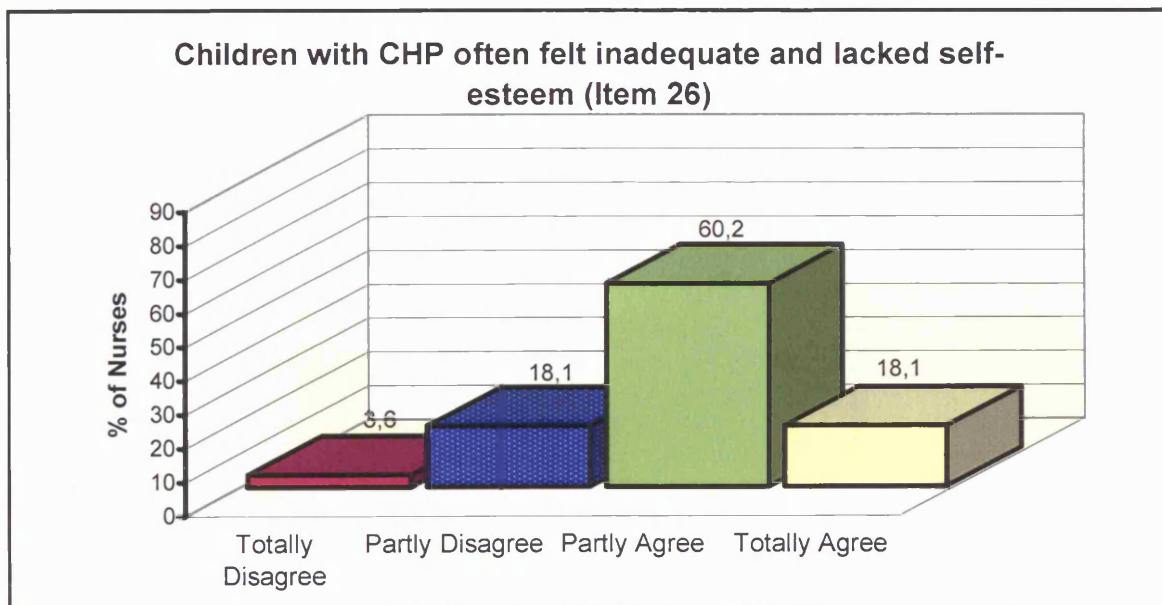


Figure 2. Nurses' Responses - Children with CHP often felt inadequate and lacked self-esteem

Item 26

Two thirds of the parents (58.2%, n=60) responded that their children felt inadequate and lacked self-esteem. A large number of the nurses (78.3%, n=65) responded that they agreed that these children felt inadequate and lacked self esteem.

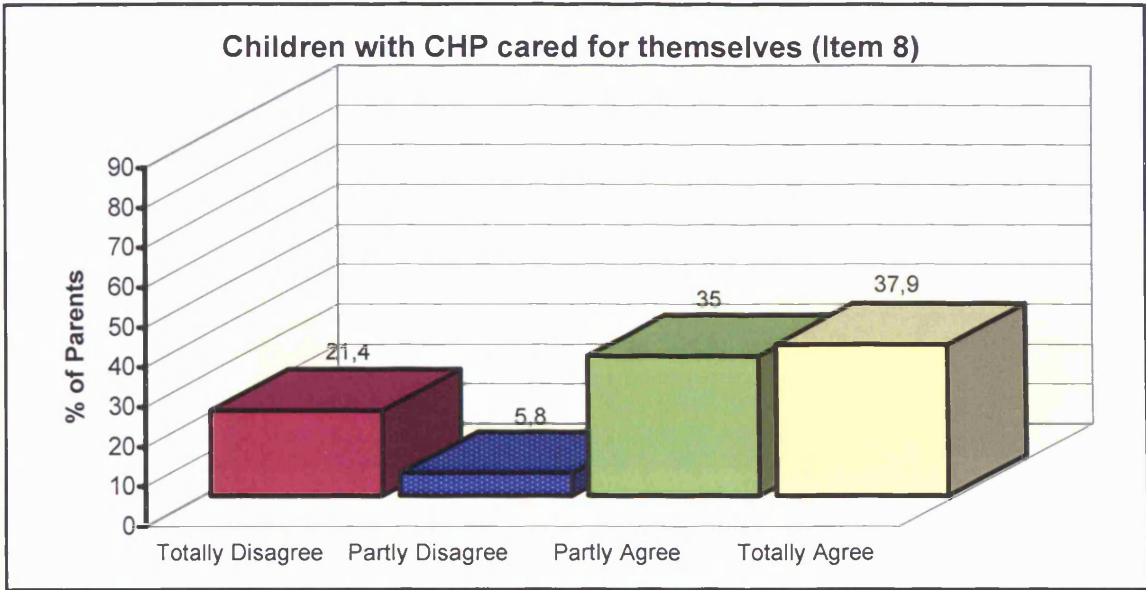


Figure 3. Parents' Responses - Children with CHP cared for themselves

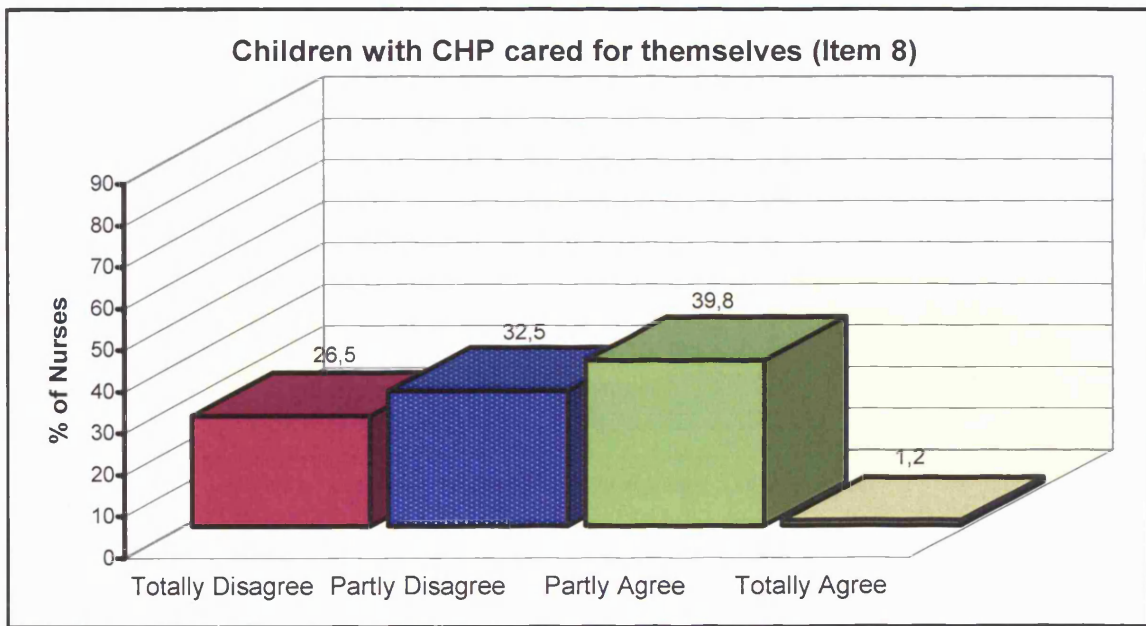


Figure 4. Nurses' Responses - Children with CHP cared for themselves

Item 8

The majority of the parents (72.8%, n=75) agreed with this statement in contrast only (40.9%, n=34) nurses agreed.

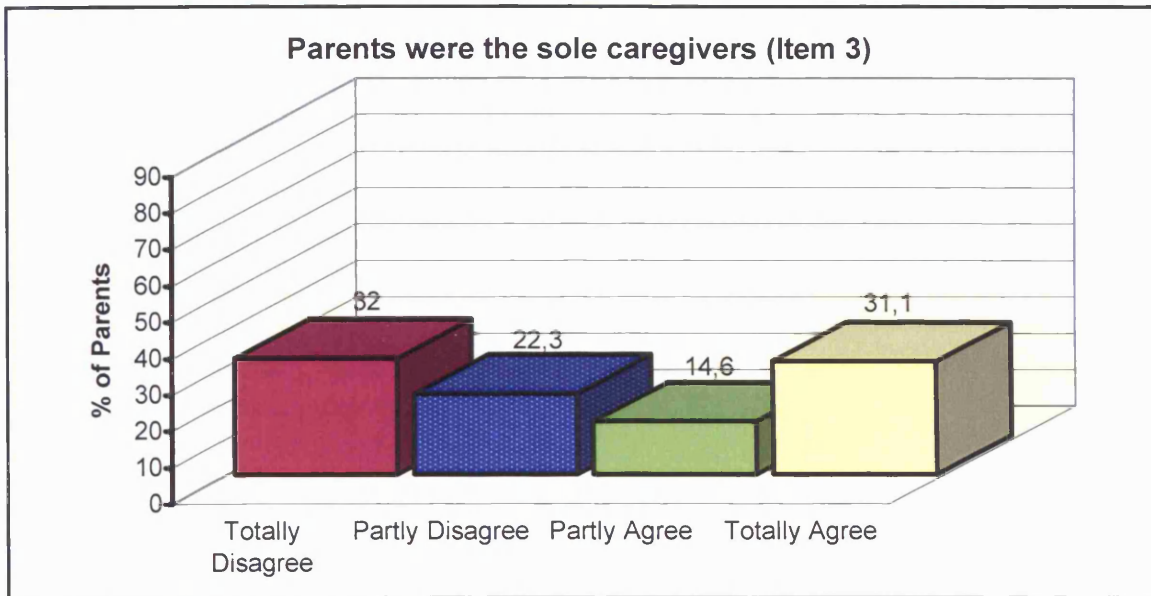


Figure 5. Parents' Responses - Parents were the sole caregivers

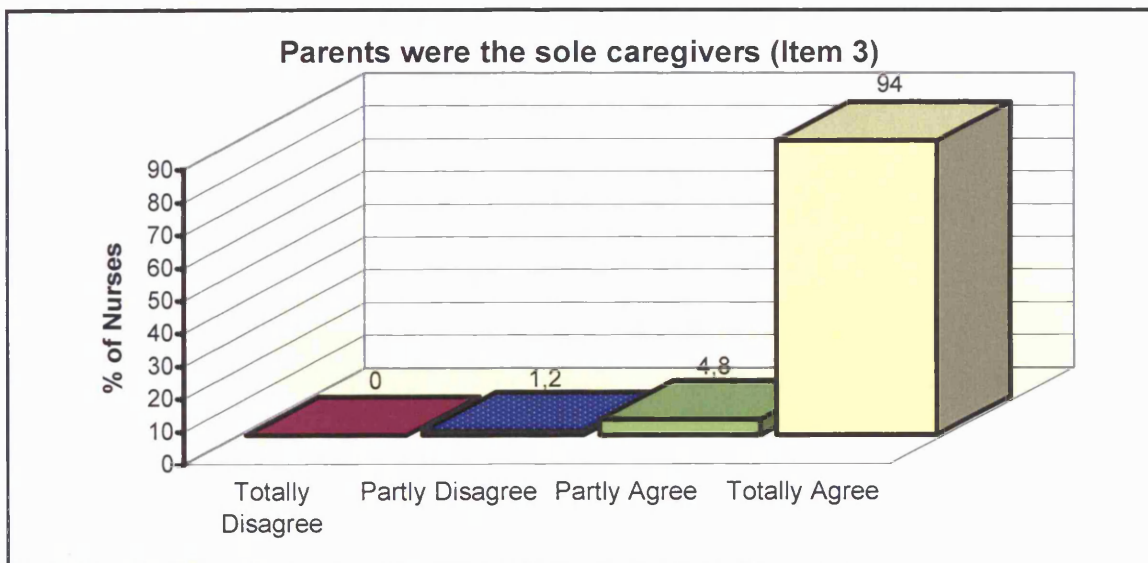


Figure 6. Nurses' Responses - Parents were the sole caregivers

Item 3

When both samples were asked if parents were the sole participants in the child's care, almost all of the nurses (98.7%, n=82) believed that the parents were the sole participants in providing their child's care, while only 47 (45.6%) parents agreed.

5.3.2. Growth and Development Including Nursing Rehabilitation

Nursing rehabilitation was included under “growth and development” since this was needed throughout the lifetime of the child, assisting the child to grow and develop to his full potential. Almost all parents supported the need for developing rehabilitation programmes (n=101), and the total of the nurses’ sample (n=83) agreed that rehabilitation programmes should be better developed.

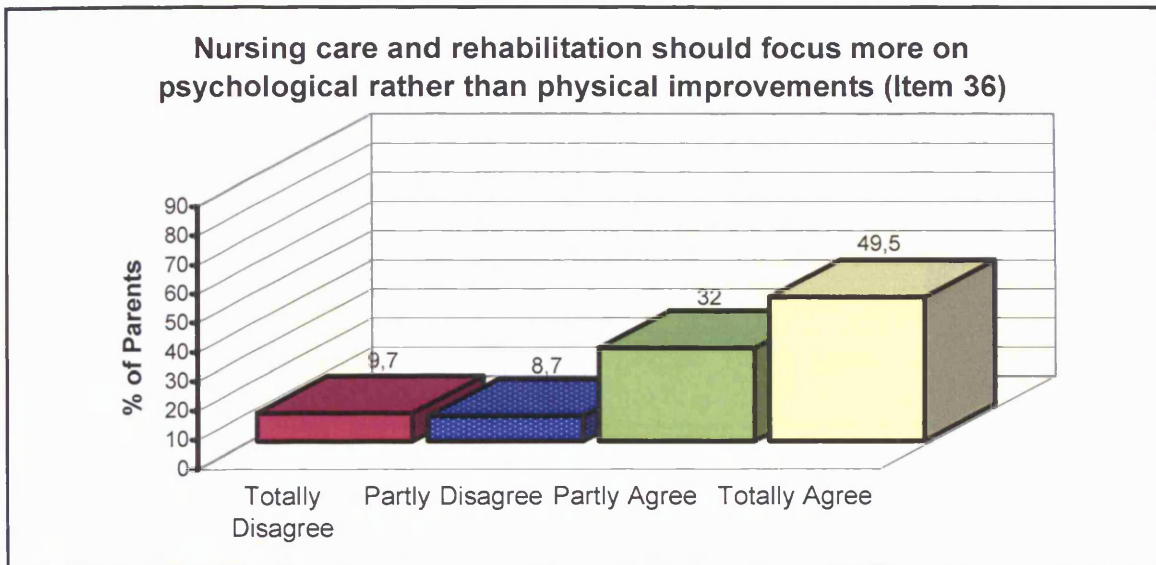


Figure 7. Parents’ Responses - Nursing care and rehabilitation should focus more on psychological rather than physical improvements

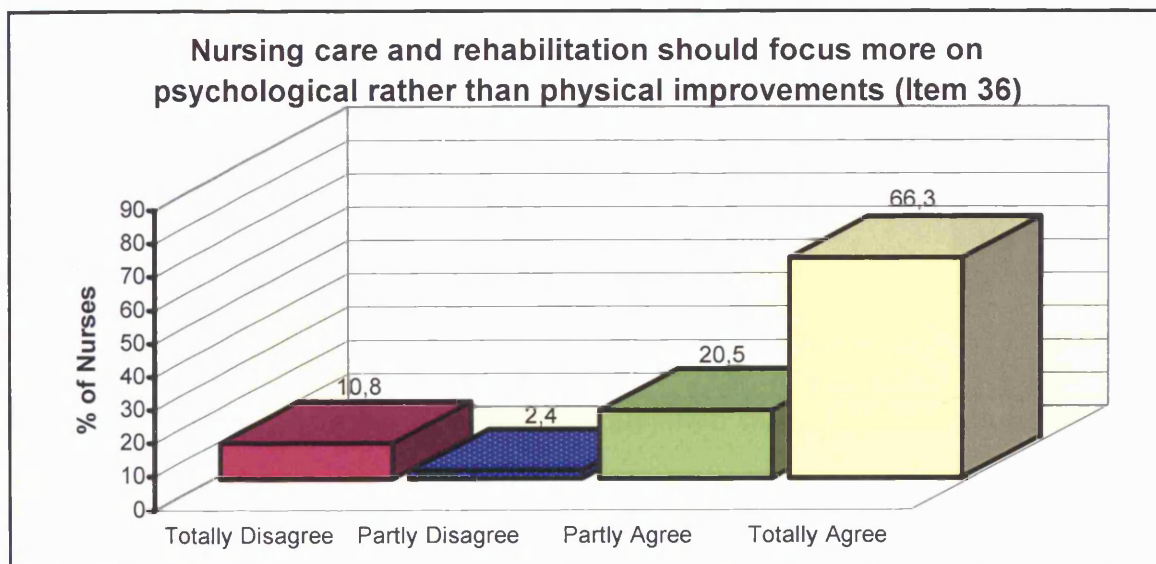


Figure 8. Nurses’ Responses - Nursing care and rehabilitation should focus more on psychological rather than physical improvements

Item 36

Concerning the need for the focus of nursing rehabilitation to be on psychological rather than physical improvements, the responses of the nurses (86.7%, n=72) and the parents (81.5%, n=84) found both samples agreeing with this statement.

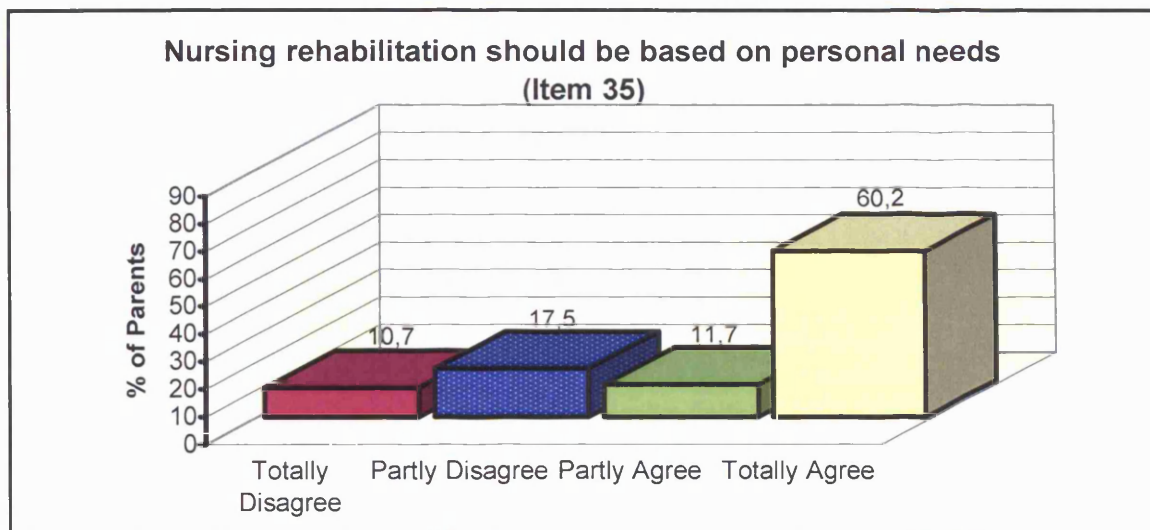


Figure 9. Parents' Responses - Nursing rehabilitation's goals should address each child's personal needs

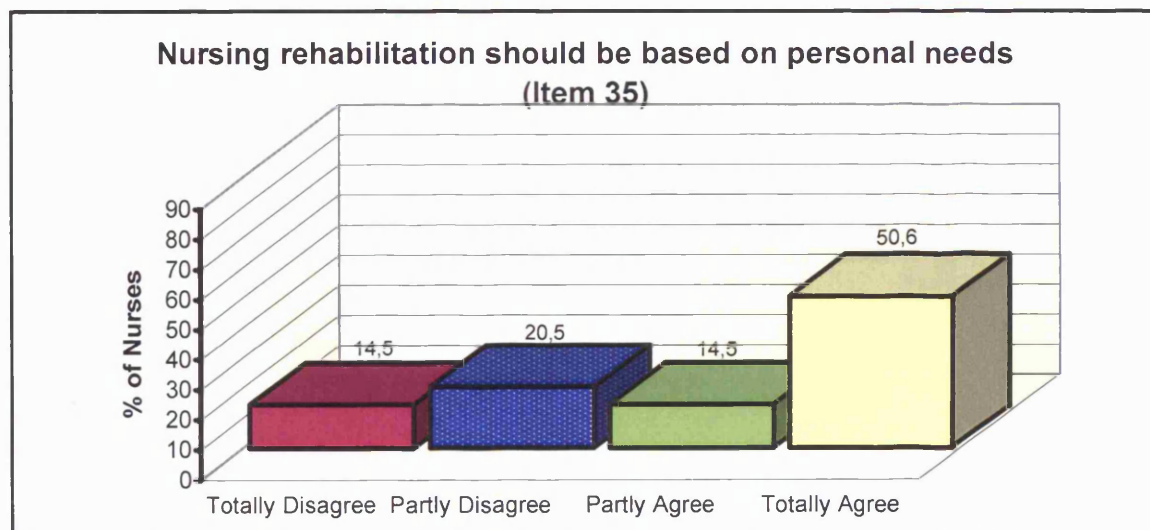


Figure 10. Nurses' Responses - Nursing rehabilitation should be based on personal needs

Item 35

Agreeing that rehabilitation goals should address each child's personal needs were 74 parents (71.8%) and 55 (66.2%) nurses.

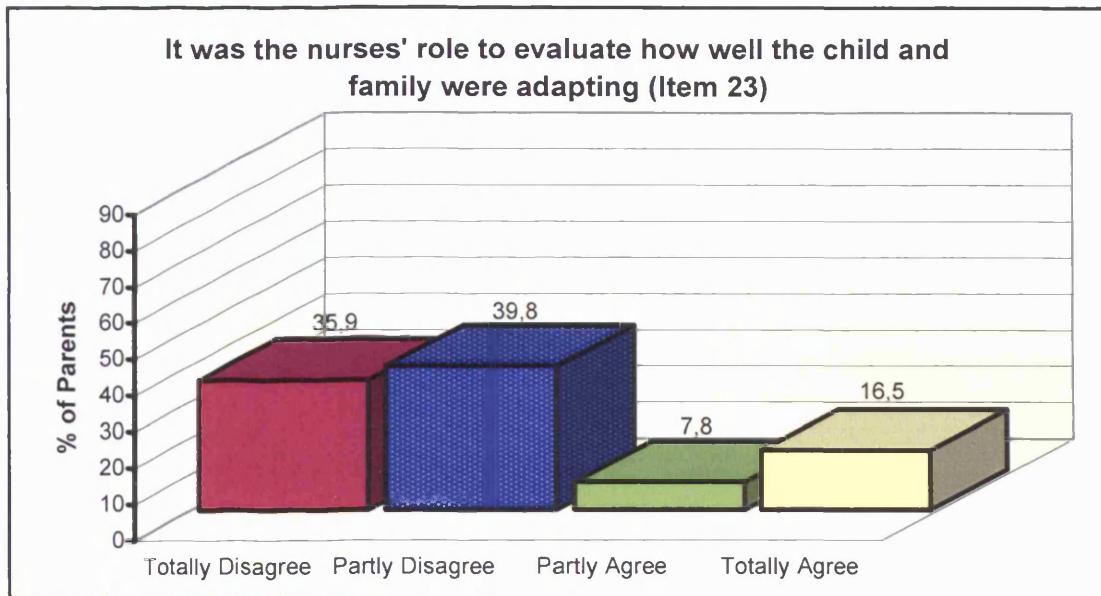


Figure 11. Parents' Responses - It was the nurses' role to evaluate how well the child and family were adapting

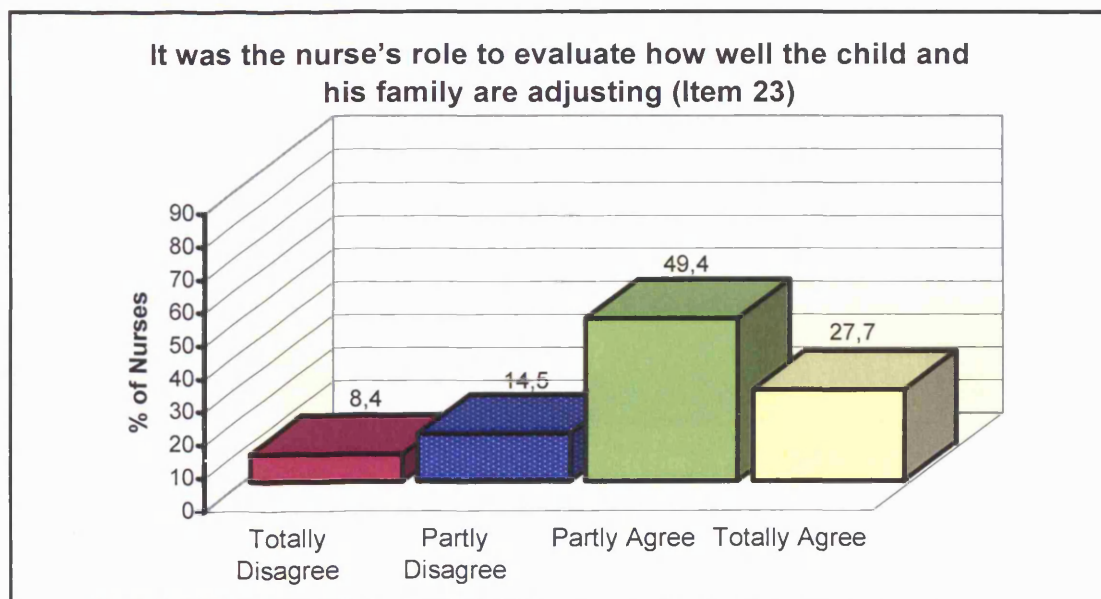


Figure 12. Nurses' Responses - It was the nurse's role to evaluate how well the child and his family are adjusting.

Item 23

The nurses (n=64) identified that evaluating the adaptation level of the child and his family as one of their roles, while a few parents (n=23) agreed.

5.3.3. Time and Space

Concerning “time”, the responses to the question concerning “future” are presented.

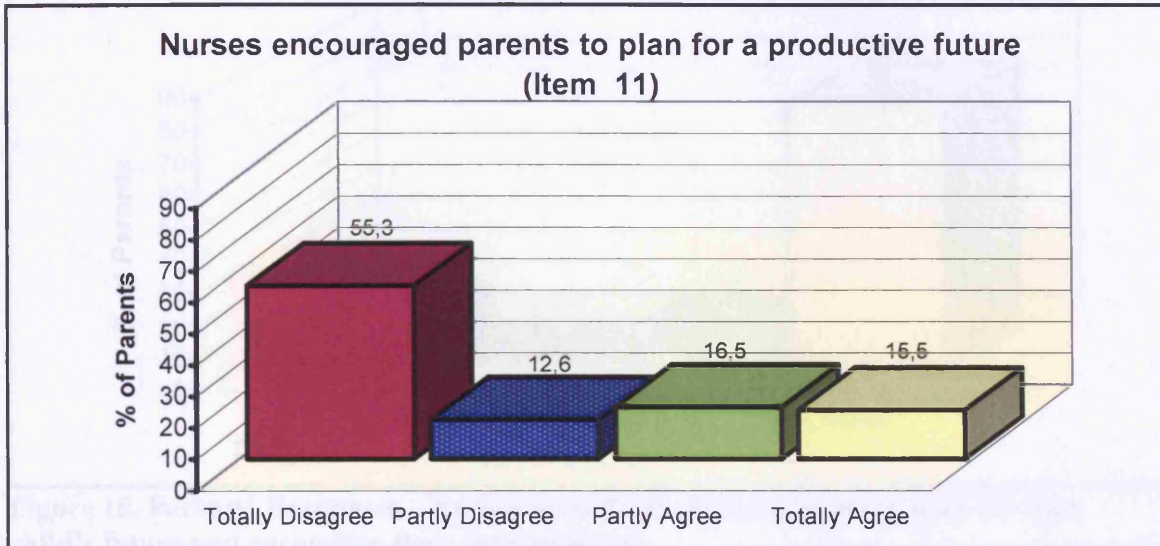


Figure 13. Parents' Responses - Nurses encouraged parents to plan for a productive future

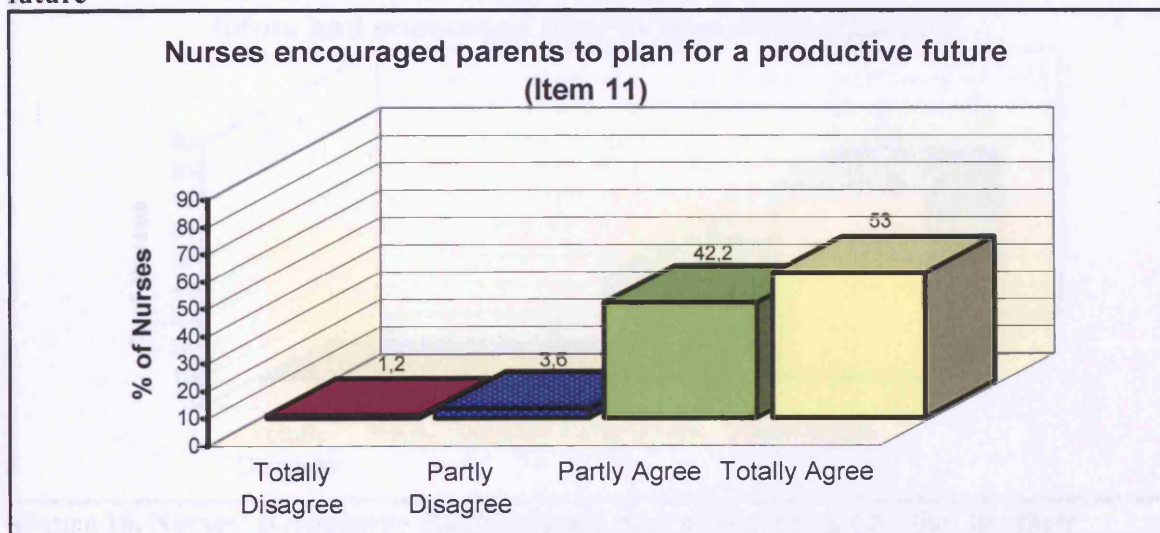


Figure 14. Nurses' Responses - Nurses encouraged parents to plan for a productive future

Item 11

Most parents agreed (89.3%, n=92), that they expected encouragement and hope (Item 18). However, only about a third of the sample (39.7%, n=33) responded that nurses had actually encouraged them to plan for their child's future (Item 11). The majority of the nurses (n=79) agreed that parents expected encouragement and hope.

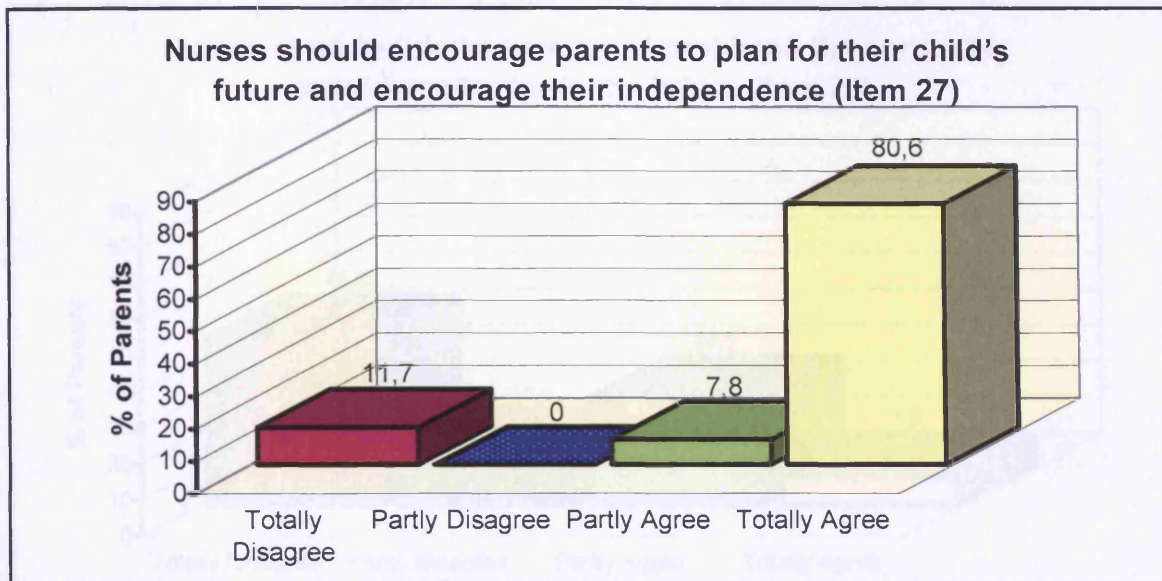


Figure 15. Parents' Responses - Nurses should encourage parents to plan for their child's future and encourage their independence

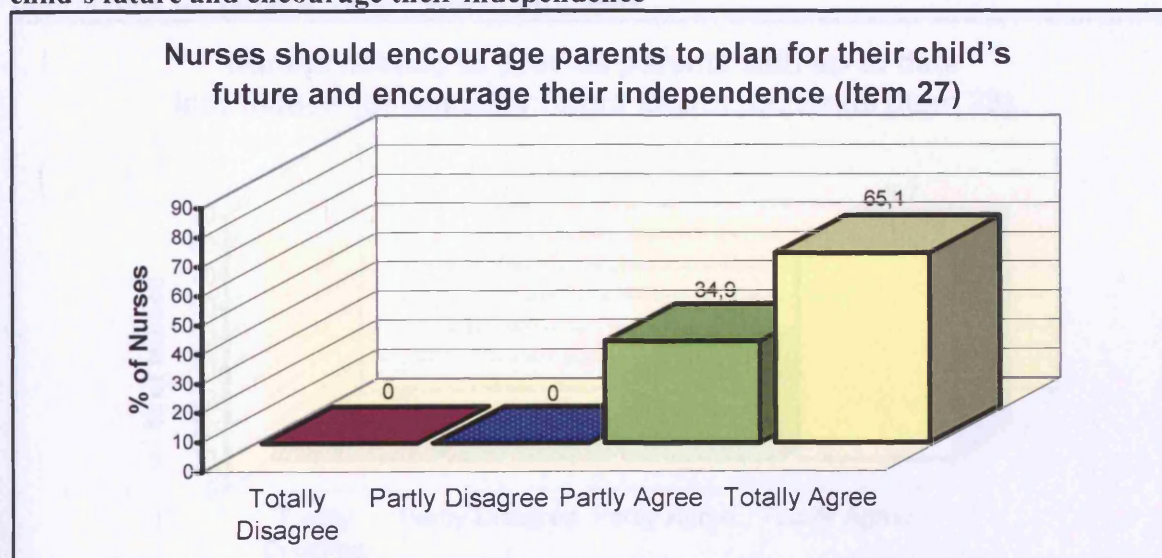


Figure 16. Nurses' Responses - Nurses should encourage parents to plan for their child's future and encourage their independence

Item 27

Many of nurses (n=79) claimed that they had offered encouragement to parents to plan for their child's future. The majority of the parents disagreed with the statement that they had been offered encouragement which demonstrates that they believe that this type of support had not been offered to them. In contrast to the parents' statements, the nurses claimed that they had offered such support to parents.

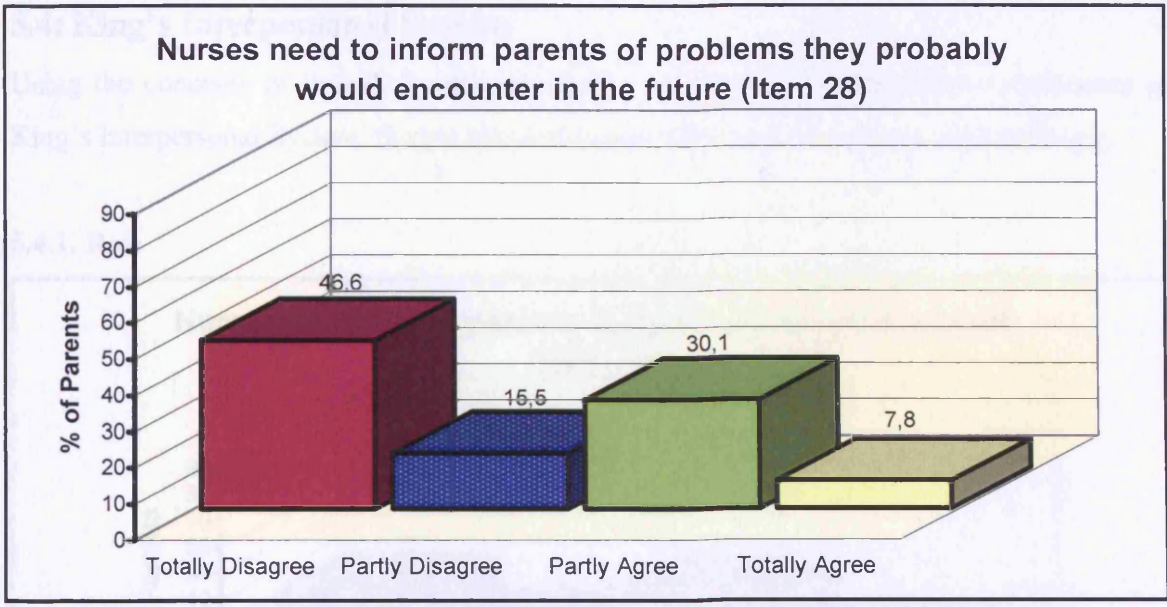


Figure 17. Parents' Responses - Nurses needed to provide parents with up to date information for possible future health problems

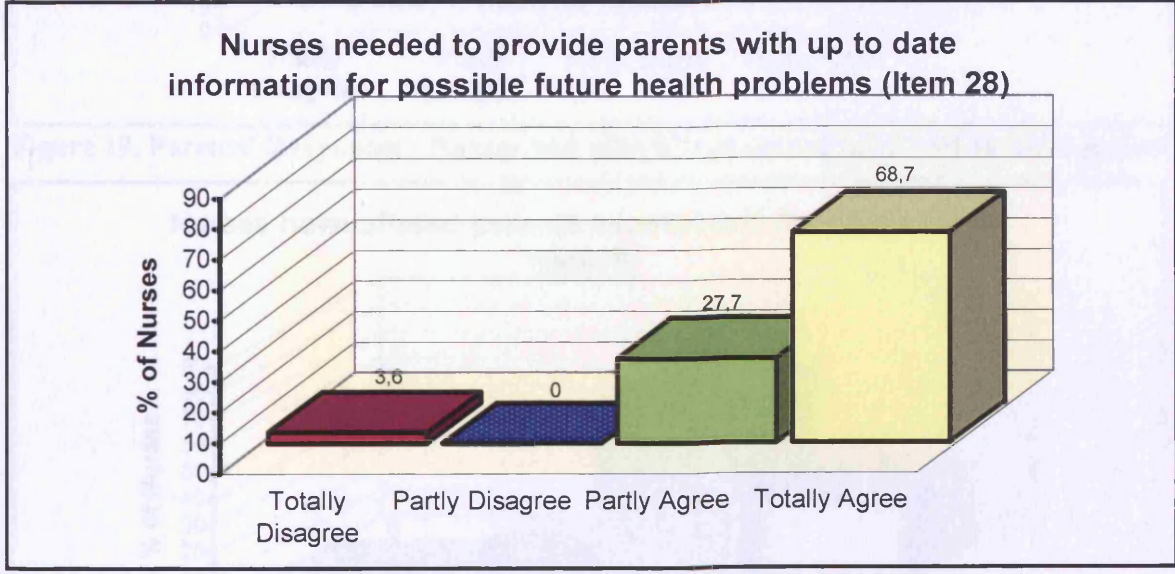


Figure 18. Nurses' Responses - Nurses needed to provide parents with up to date information for possible future health problems

Item 28

Another issue of importance to this study was the role of the nurse in providing up to date information concerning future health problems that might arise. The nurses appeared (96.3%, n=80) to recognize this as their role while only a minority of the parents (30%, n=31) agreed that this was a part of the nursing role.

5.4. King's Interpersonal System

Using the concepts of "role", "communication", and "stress" as identified components of King's Interpersonal System, the parents and nurses responses are presented accordingly.

5.4.1. Role

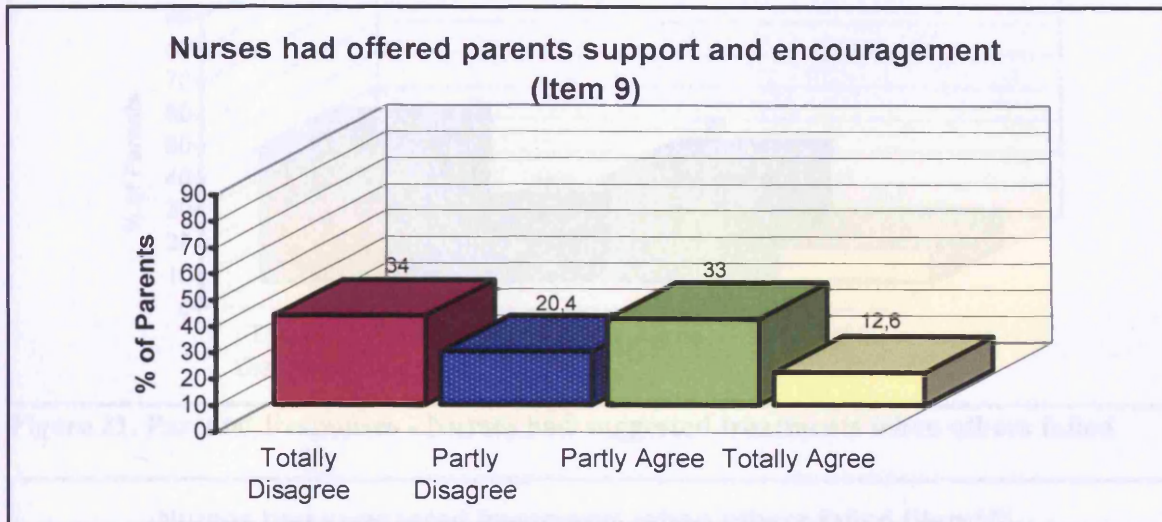


Figure 19. Parents' Responses - Nurses had offered parents support and encouragement

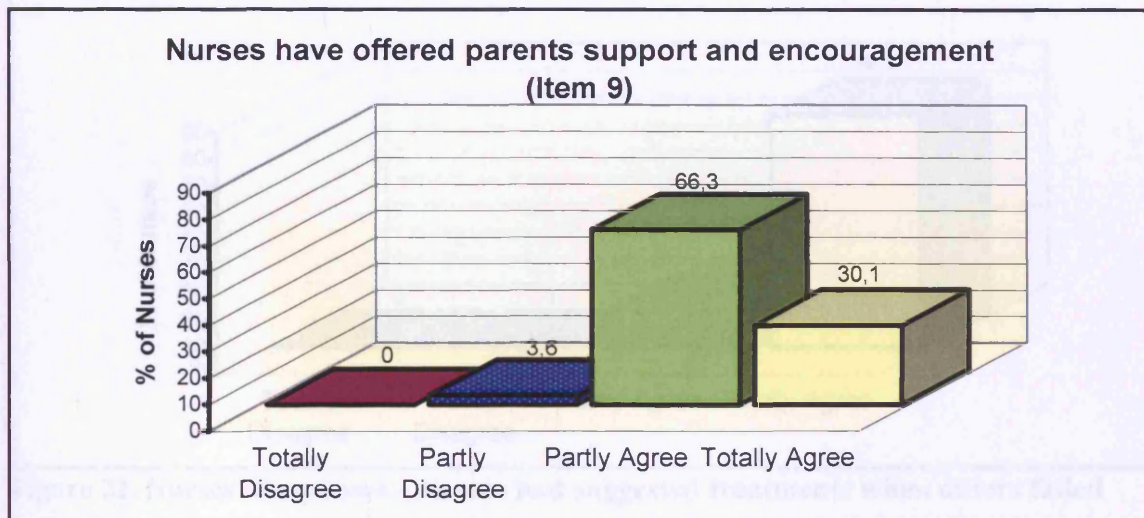


Figure 20. Nurses' Responses -Nurses had offered parents support and encouragement

Items 9

Approximately half of the sample of parents (n=47) agreed that nurses had offered them support and encouragement, while only 37 parents claimed that nurses had been encouraged

them over a long period of time. Almost the entire sample of nurses (n=80) felt that they had offered parents support and encouragement.

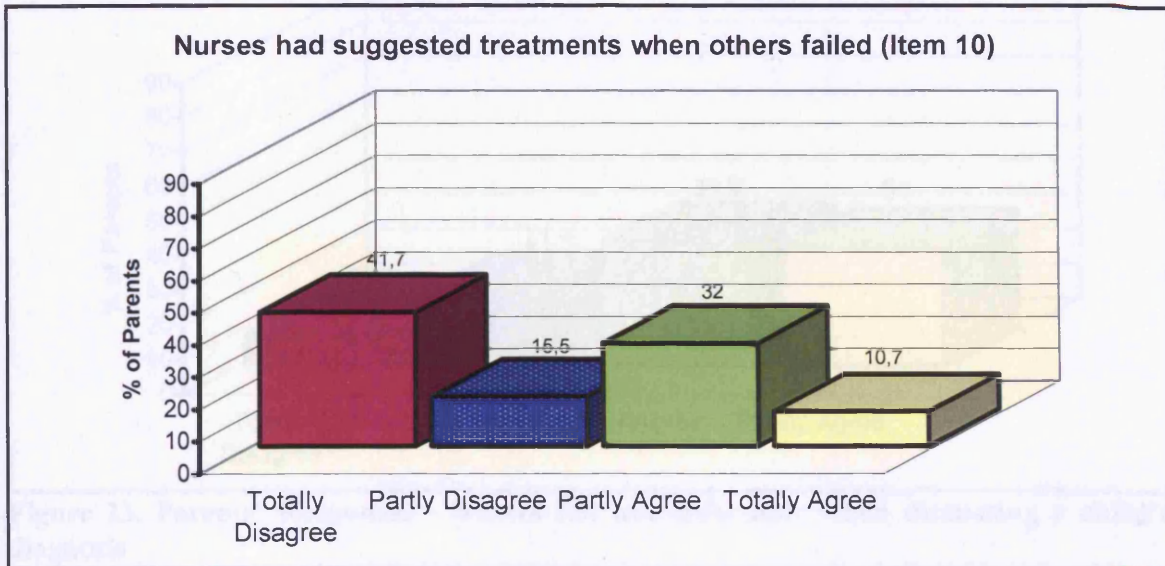


Figure 21. Parents' Responses - Nurses had suggested treatments when others failed

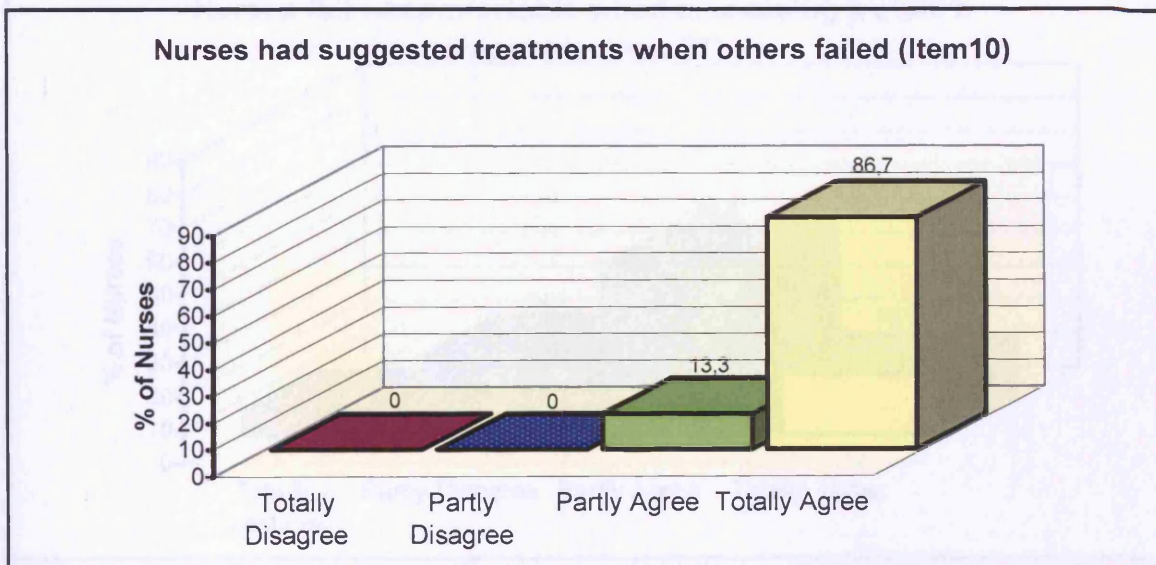


Figure 22. Nurses' Responses - Nurses had suggested treatments when others failed

Item 10

Some parents (42.7%, n=44) agreed that nurses had offered other treatment regimes when one method had failed. The entire sample of nurses (100%, n=83) agreed that they had offered parents other treatment regimes when one method failed.

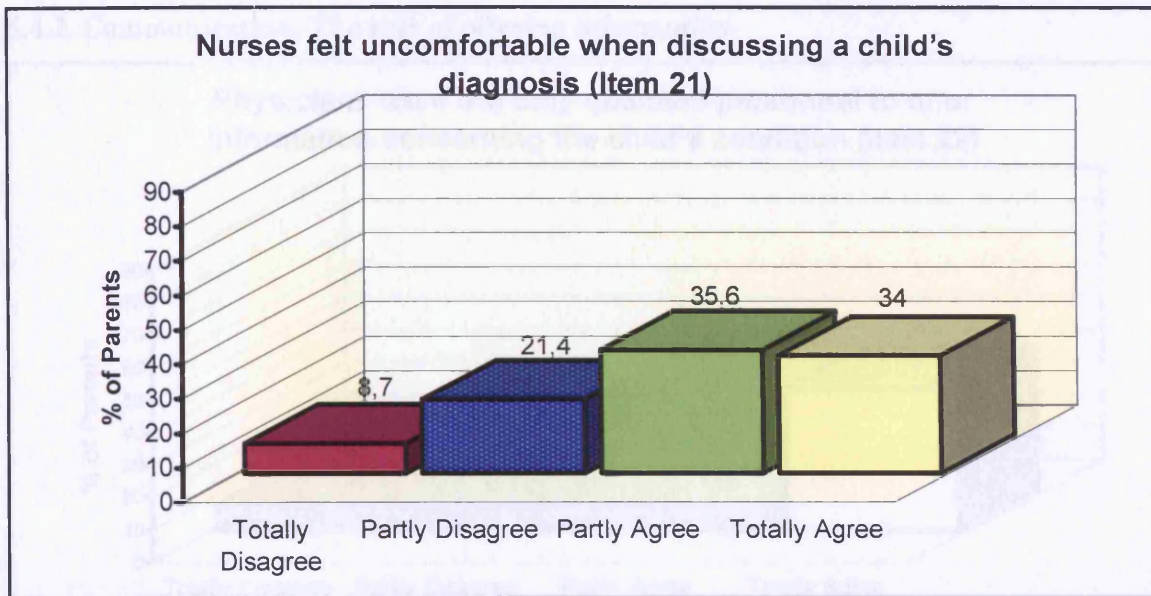


Figure 23. Parents' Responses - Nurses felt uncomfortable when discussing a child's diagnosis

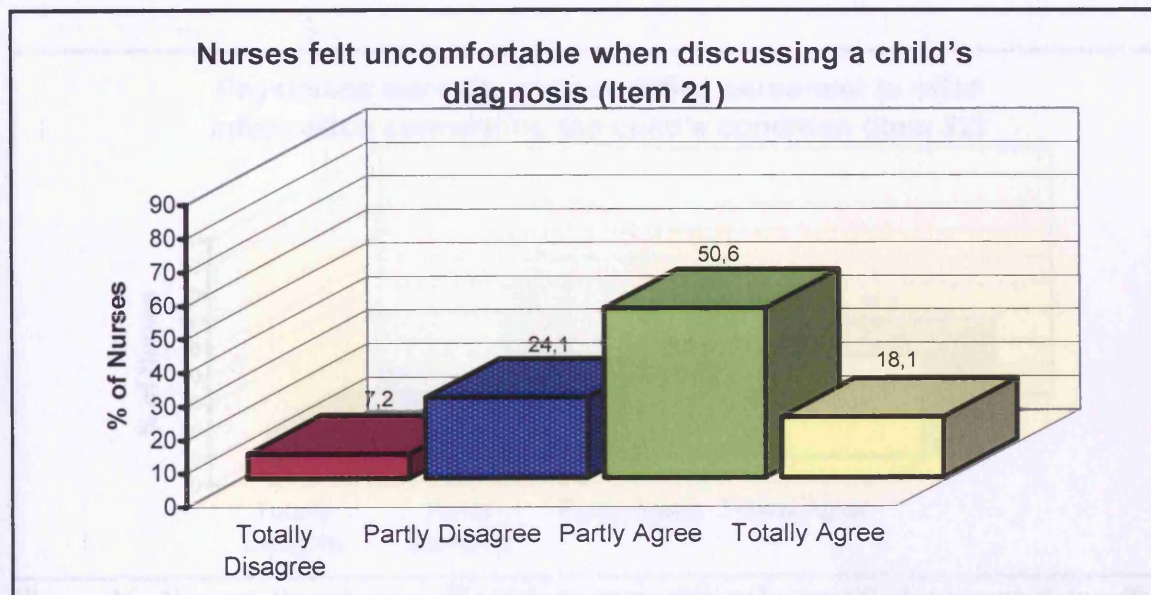


Figure 24. Nurses' Responses - Nurses felt uncomfortable when discussing a child's diagnosis

Item 21

Most parents agreed (67%, n=72) that nurses felt uncomfortable when talking to them about their child's diagnosis. More than half of the sample of nurses (68.6%, n=57) agreed that they felt uncomfortable when they were talking to parents about their child's diagnosis.

5.4.2. Communication: The role of offering information

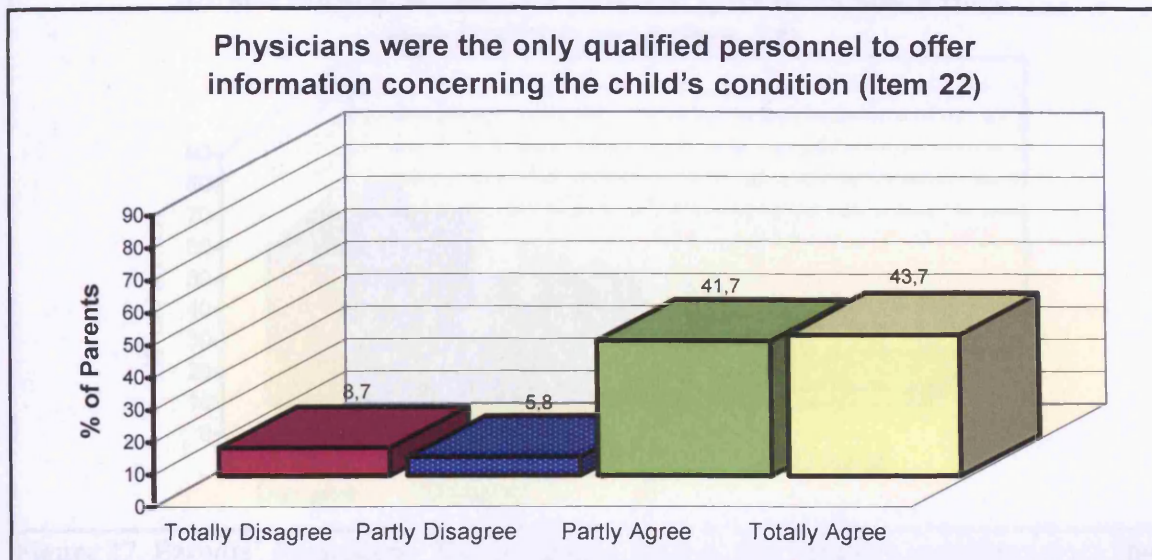


Figure 25. Parents' Responses - Physicians were the only qualified personnel to offer information concerning the child's condition

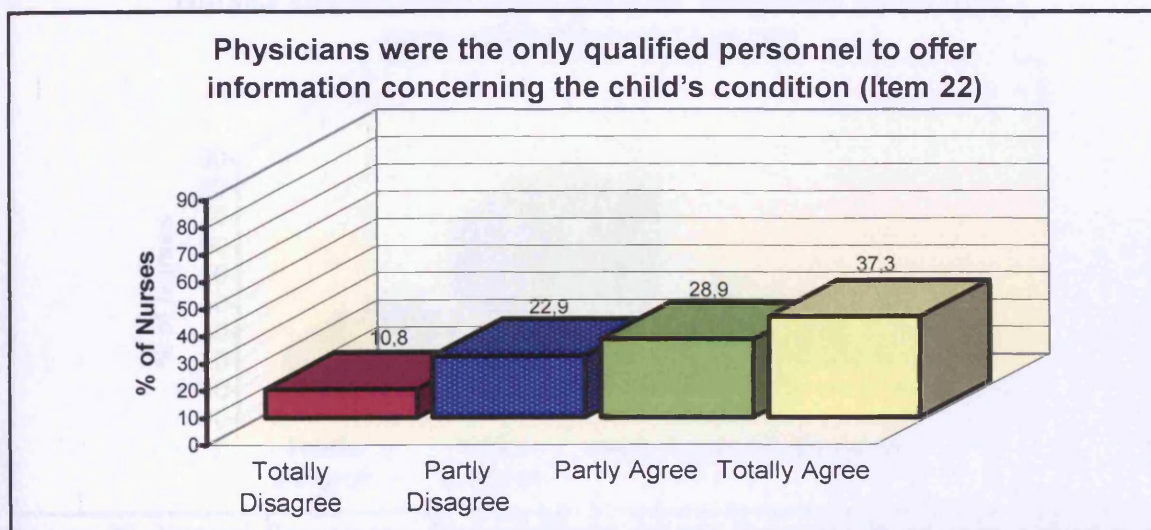


Figure 26. Nurses' Responses - Physicians were the only qualified personnel to offer information concerning the child's condition

Item 22

A majority of the parent sample (85.4%, n=88) felt that physicians were the only qualified professionals capable of offering information concerning their children's condition, and a majority of the nurses sample (66.2%, n=55) agreed.

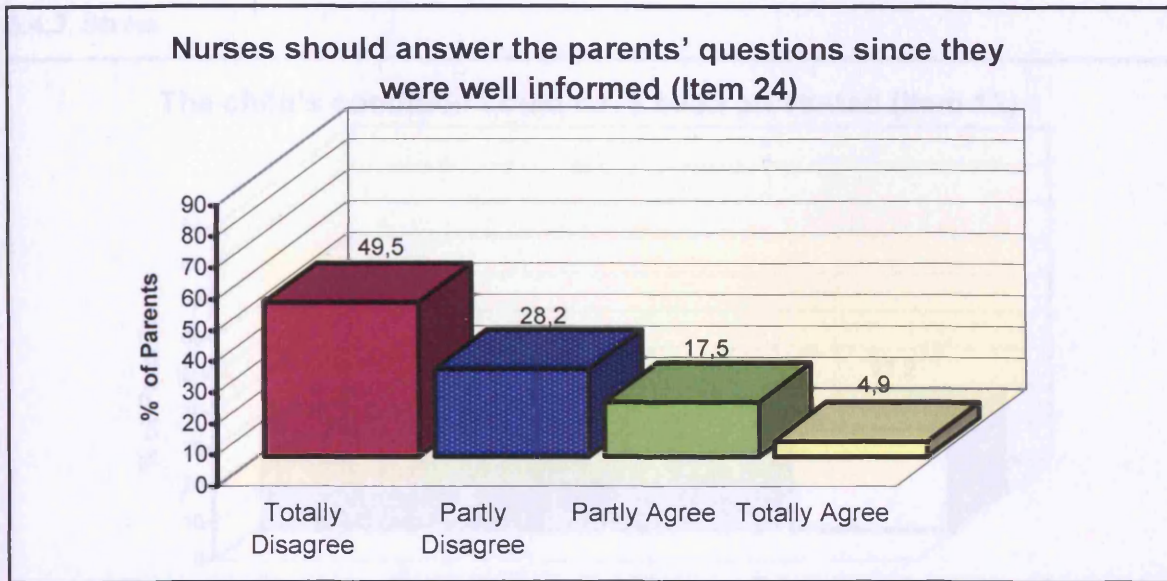


Figure 27. Parents' Responses - Nurses should answer the parent's questions since they were well informed

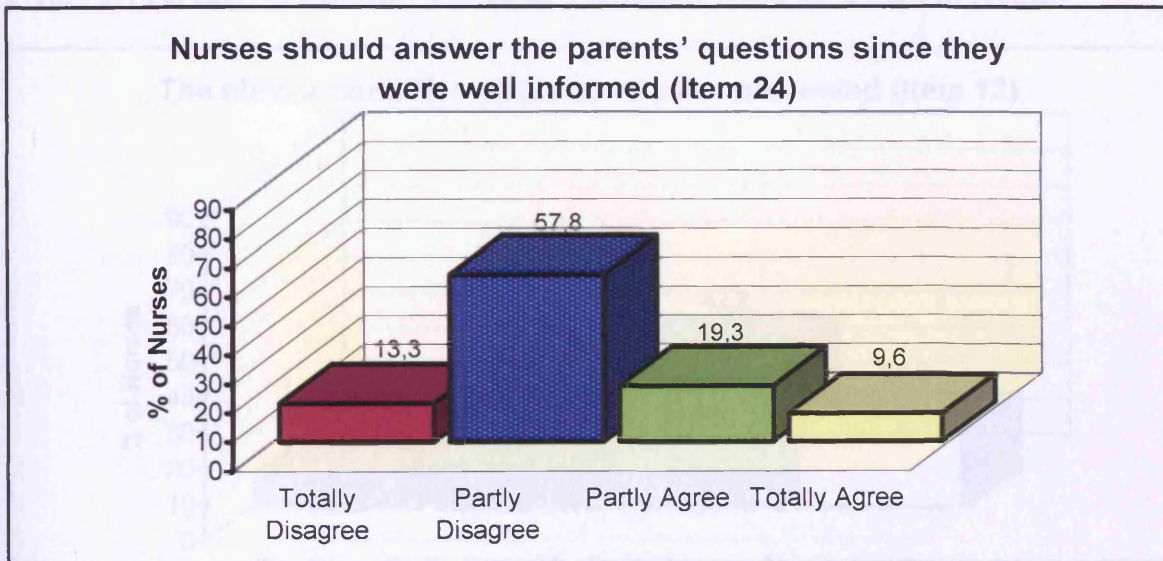


Figure 28. Nurses' Responses - Nurses should answer the parent's questions since they were well informed

Item 24

Only a few parents (22.3%, n=23) believed that nurses were well enough informed to answer their questions. Unfortunately, only a few of the nurses (29%, n=24) believed that nurses were well enough informed to answer the parents' questions. Since the majority of the nurses and the parents disagree with this item it might suggest that both groups felt that this was not a role the nurse should undertake.

5.4.3. Stress

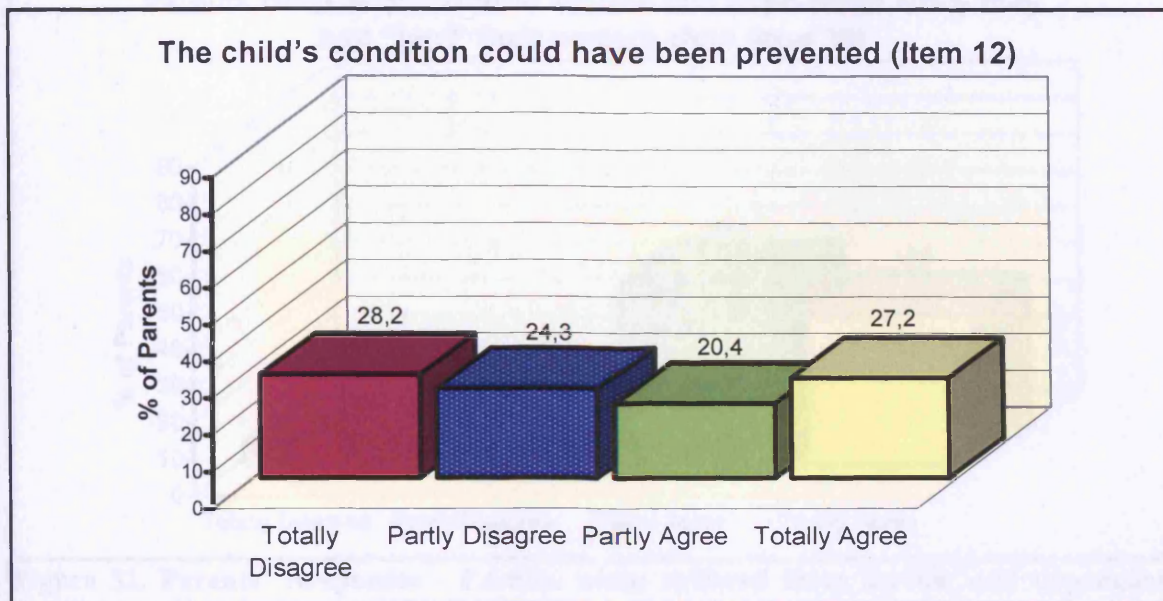


Figure 29. Parents' Responses - The child's condition could have been prevented

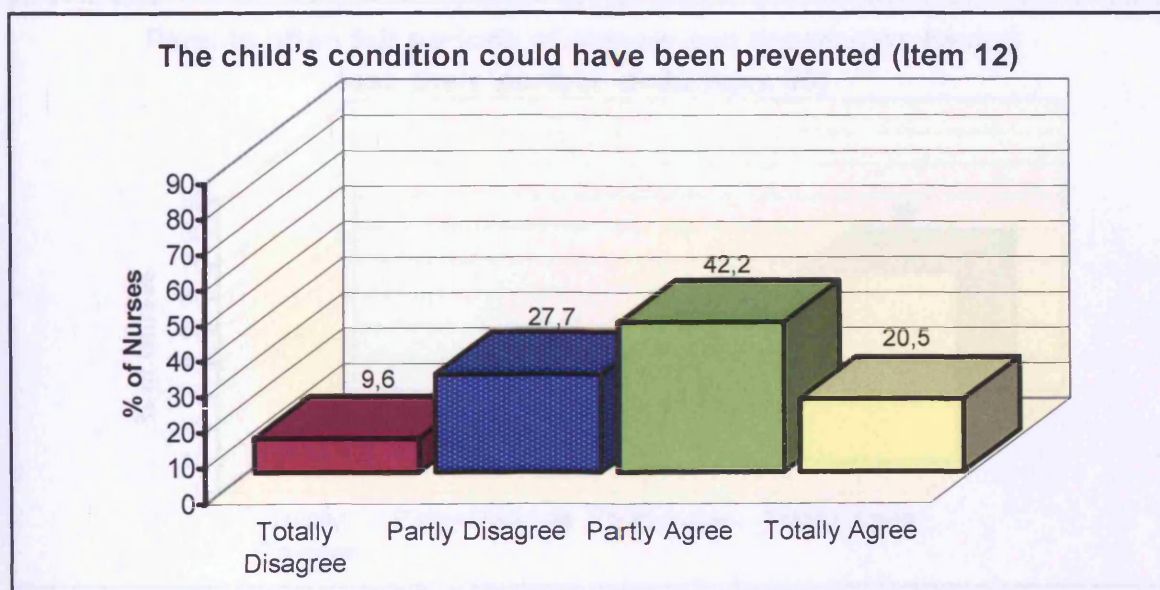


Figure 30. Nurses' Responses - The child's condition could have been prevented

Item 12

There were indications that two-thirds (n=52) of the nurses agreed with this while almost fifty percent (n=49) of the parents agreed.

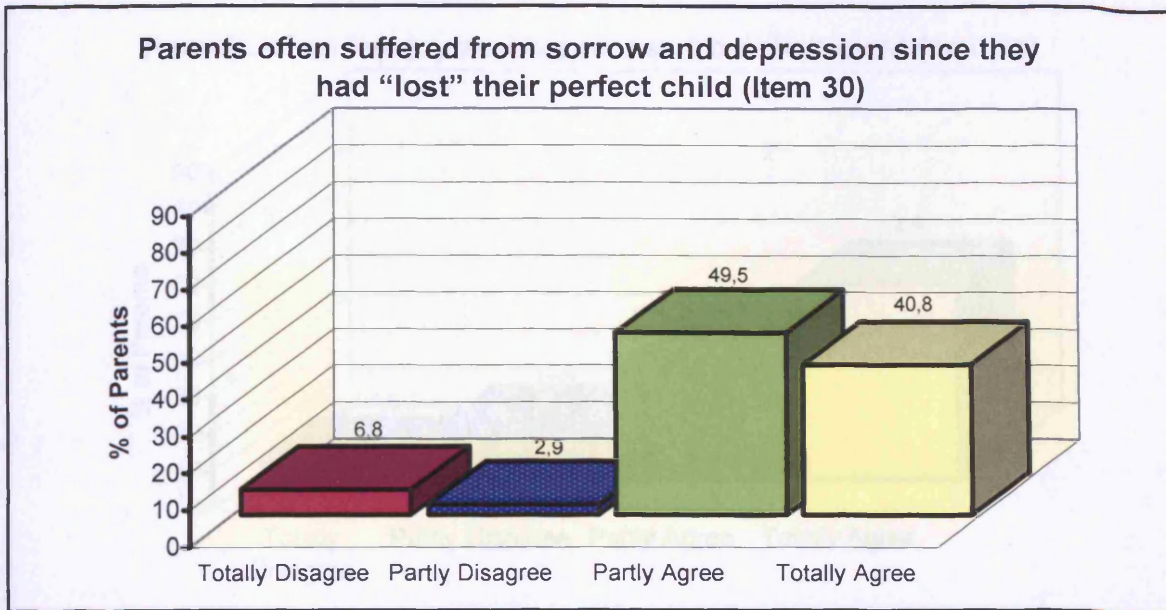


Figure 31. Parents' Responses - Parents often suffered from sorrow and depression since they had "lost" their perfect child

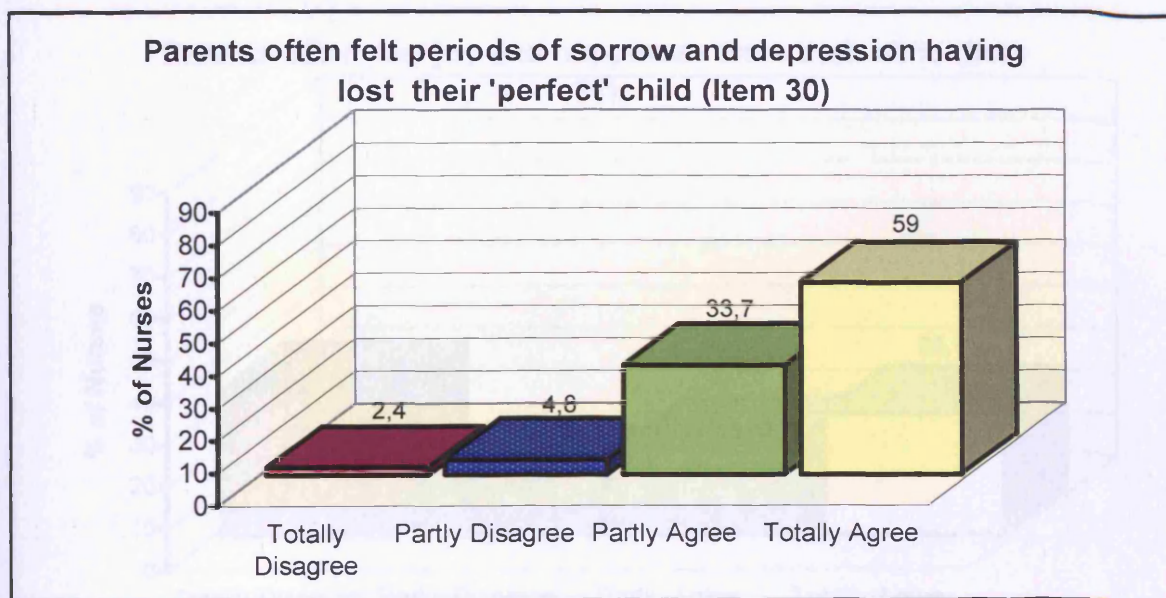


Figure 32. Nurses' Responses - Parents often felt periods of sorrow and depression having lost of their 'perfect' child

Item 30

Most of the parents (n=93) expressed feeling periods of sorrow and depression for having lost their "perfect" child. Most of the nurses (n=77) agreed that parents often felt periods of sorrow and depression.

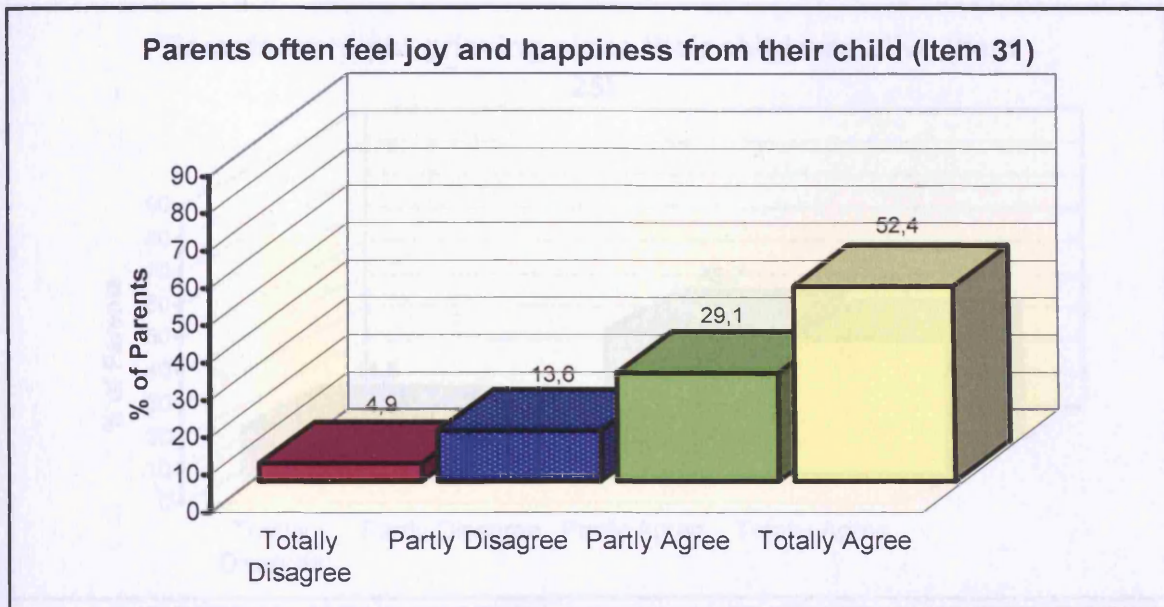


Figure 33. Parents' Responses - Parents often feel joy and happiness from their child

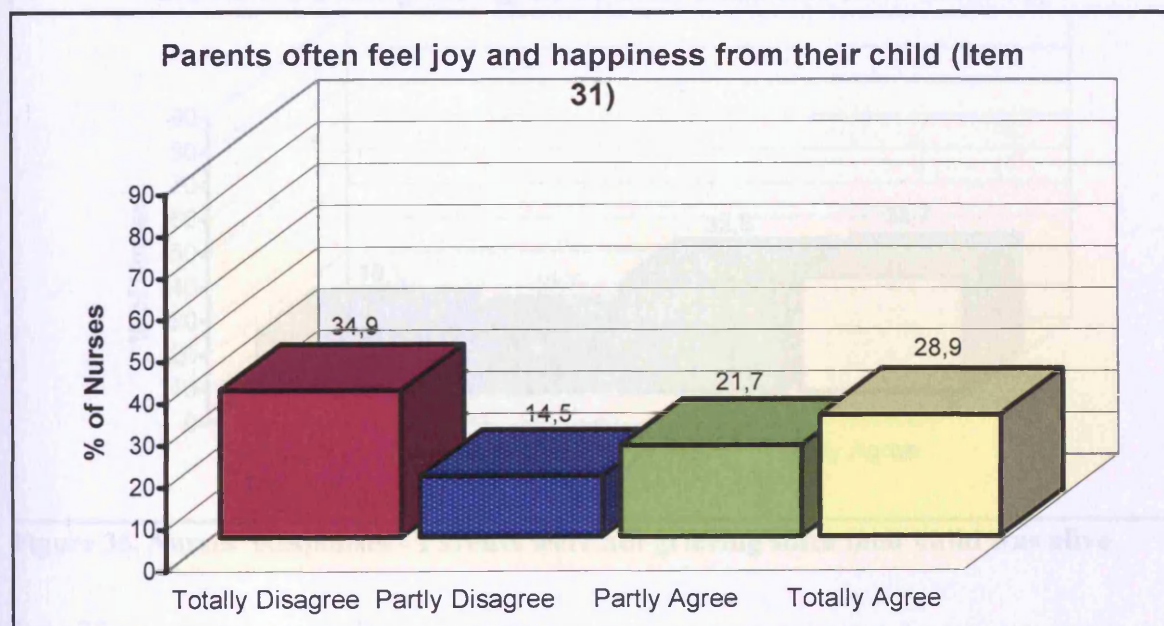


Figure 34. Nurses' responses - Parents often feel joy and happiness from their child

Item 31

A majority of the parents (n=83) expressed receiving "joy and happiness" from their children. Only half of the total sample of nurses (n=42) agreed that parents received joy and happiness from their child.

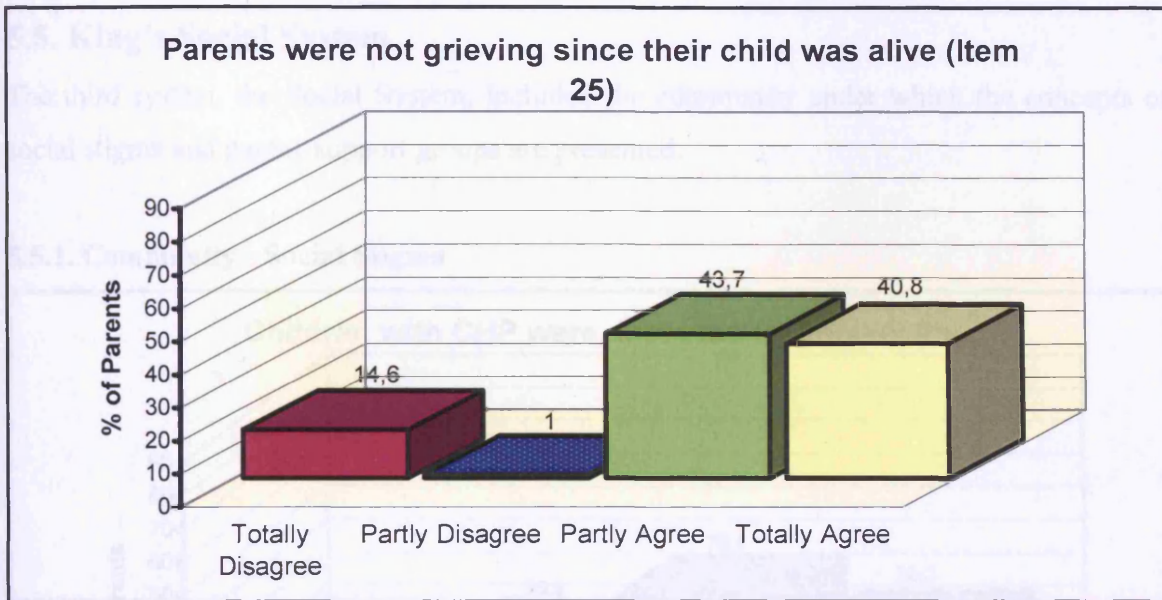


Figure 35. Parents' Responses - Parents were not grieving since their child was alive

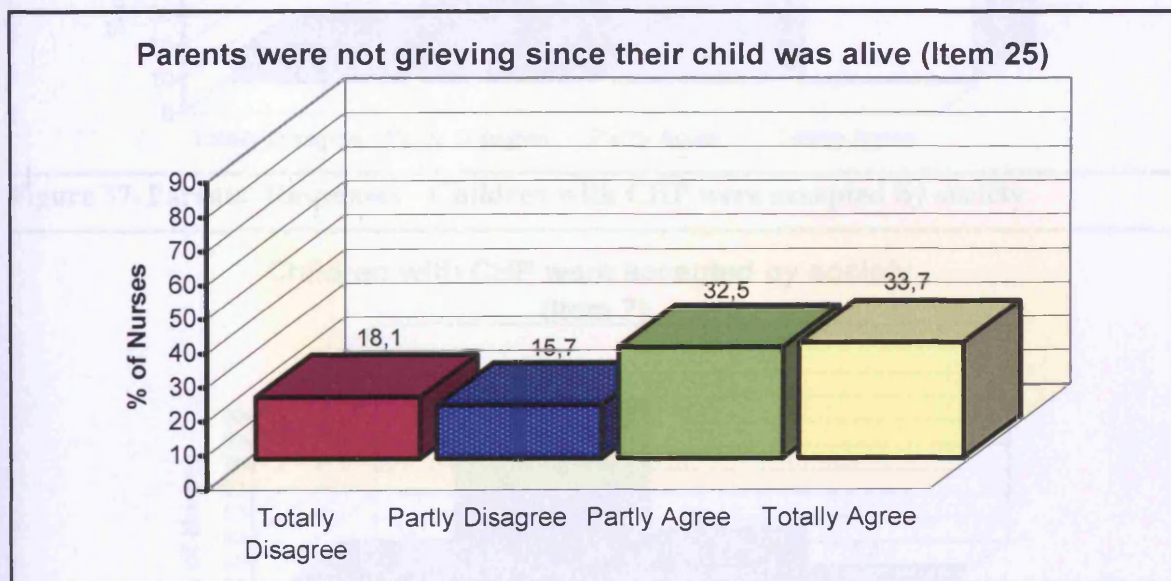


Figure 36. Nurses' Responses - Parents were not grieving since their child was alive

Item 25

More than half of the sample of nurses (n=55) agreed that they did not need to understand chronic sorrow. It appeared that the majority of the parents and two-thirds of the nurses did not understand the grieving process that these parents usually experience. The majority of both samples agreed that such feelings were not experienced by the parents, which was in contrast to the literature and will be explicitly discussed in the following chapter.

5.5. King's Social System

The third system, the Social System, included the community under which the concepts of social stigma and parent-support groups are presented.

5.5.1. Community - Social Stigma

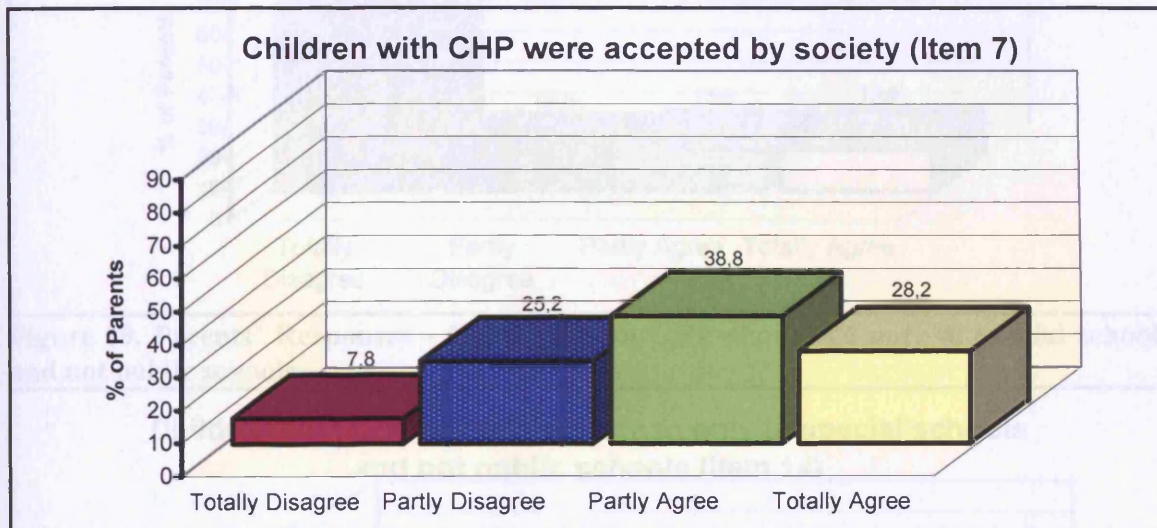


Figure 37. Parents' Responses - Children with CHP were accepted by society

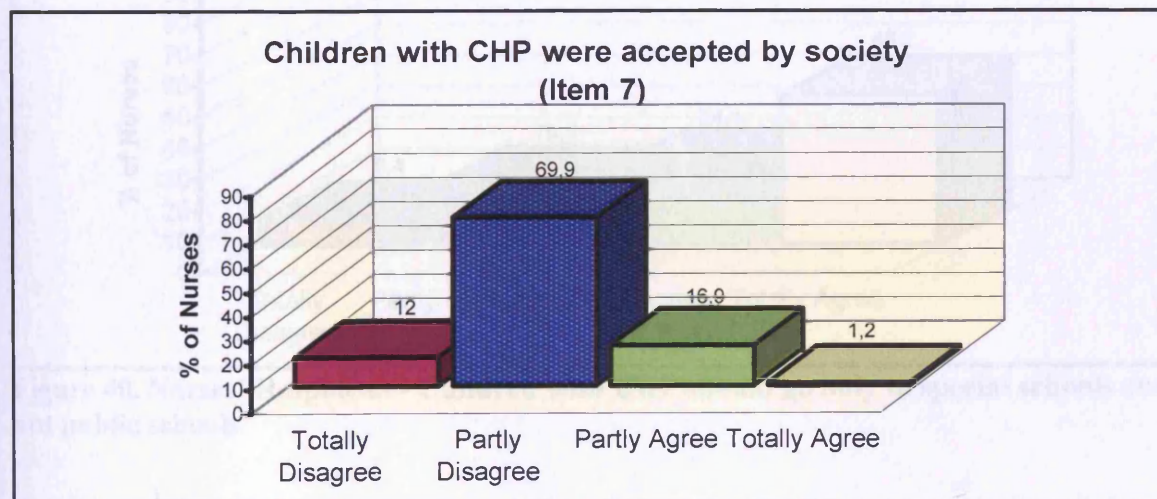


Figure 38. Nurses' Responses - Children with CHP were accepted by society

Item 7

The majority of the parents (67%, n=69) reported that they felt their child was accepted within the community, yet few of the nurses (18%, n=15) felt the community accepted them.

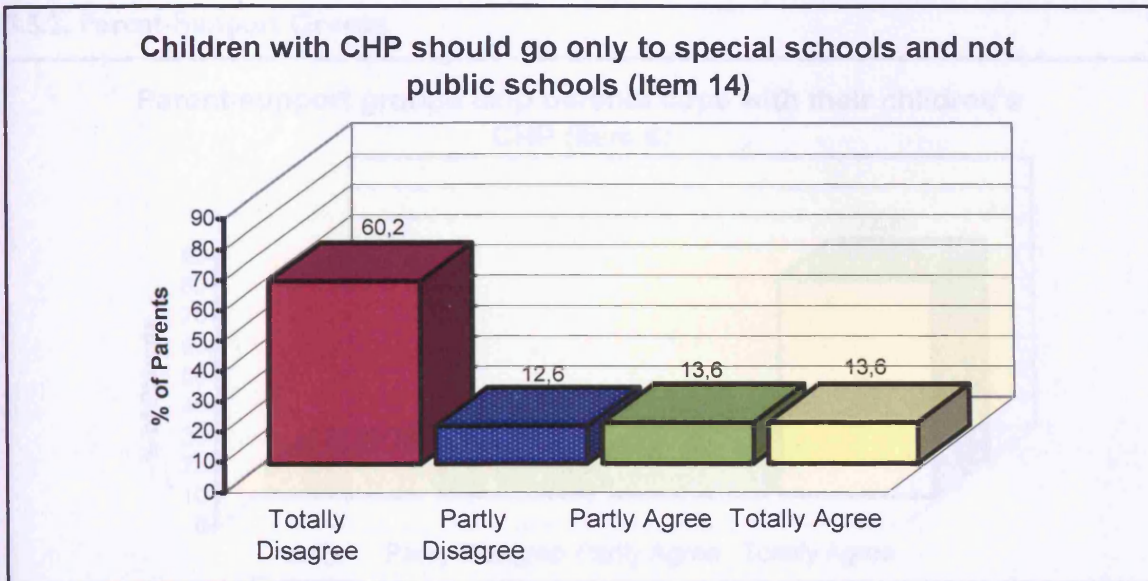


Figure 39. Parents' Responses - Children with CHP should go only to special schools and not public schools

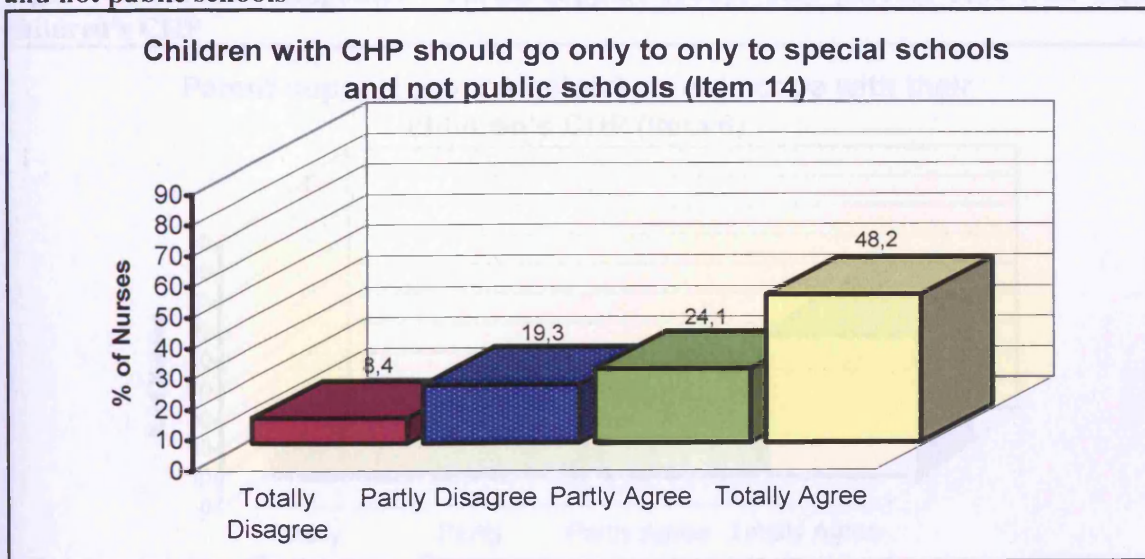


Figure 40. Nurses' Responses - Children with CHP should go only to special schools and not public schools

Item 14

The majority of the parent sample (72.8%, n=75) believed that children with CHP should attend only regular schools, only a few parents (27.1%, n=28) believed that their children should attend a special school. Most nurses (n=60) believed that these children should attend special schools.

5.5.2. Parent-Support Groups

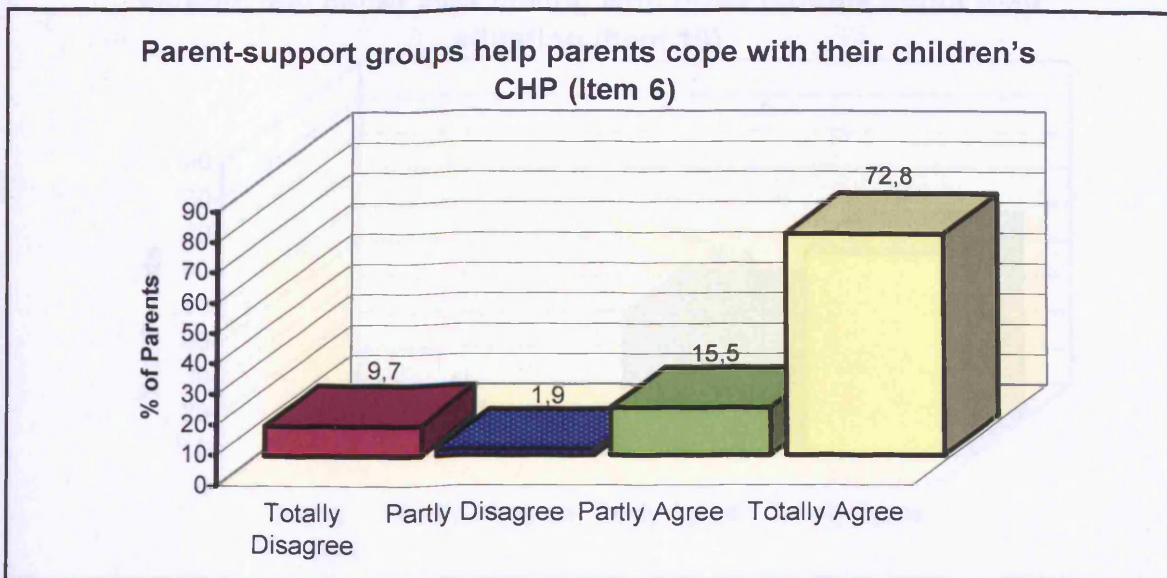


Figure 41. Parents' Responses - Parent-support groups help parents cope with their children's CHP

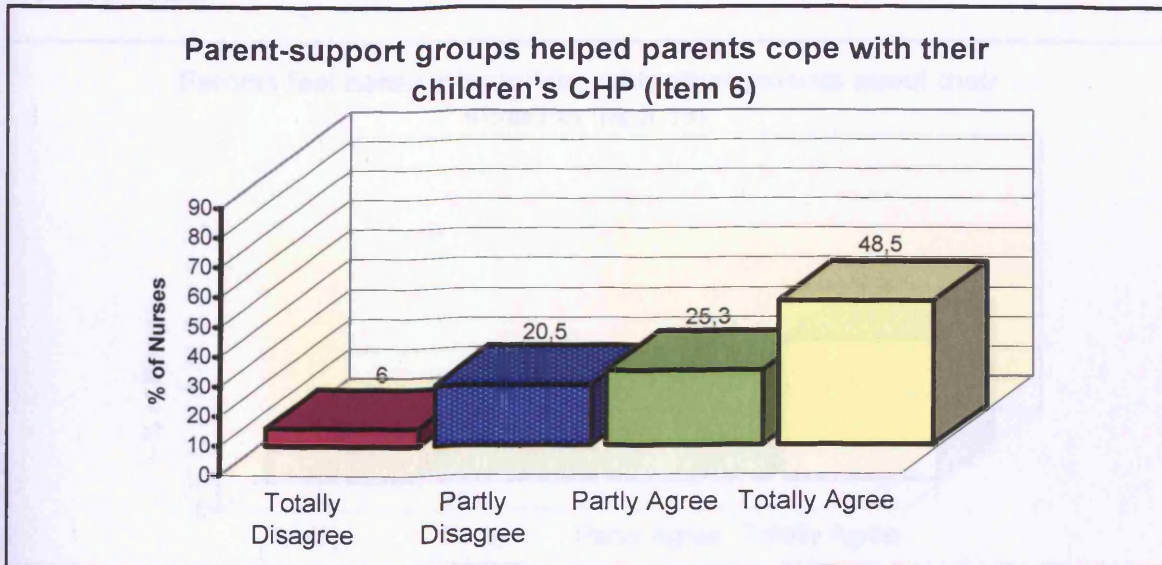


Figure 42. Nurses' Responses - Parent-support groups helped parents cope with their children's CHP

Item 6

The majority of parents (n=91) agreed that parent-support groups offered positive results and helped with the coping of their child's condition. The majority of the nurses' sample (n=61) agreed. Both samples supported this belief, however, a larger percentage of the parents agreed.

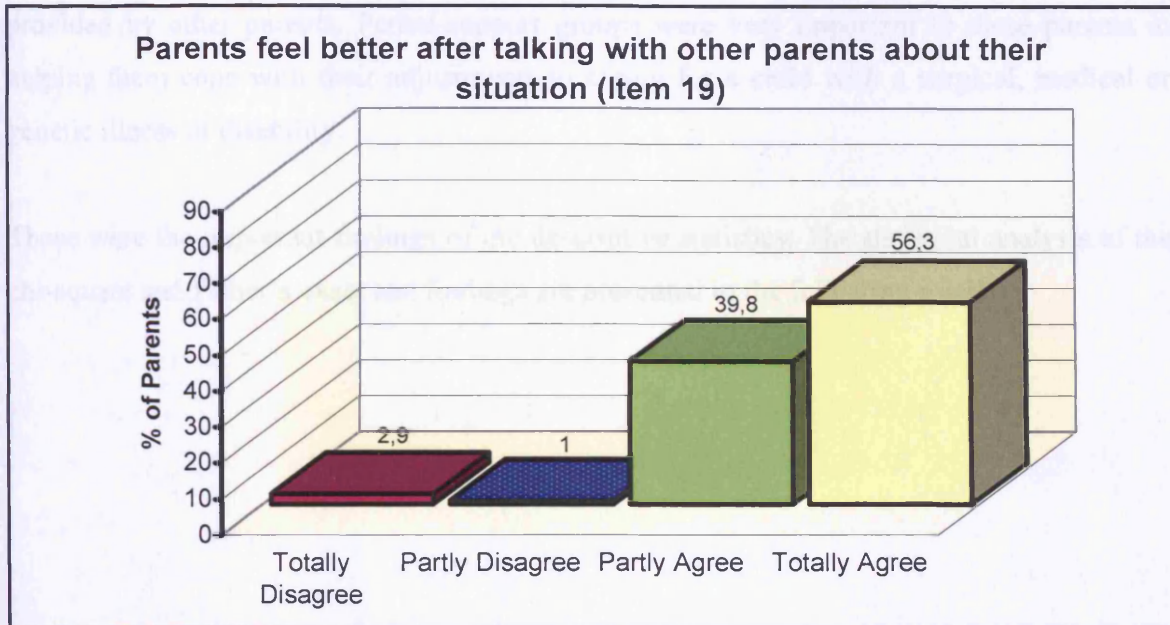


Figure 43. Parents' Responses - Parents feel better after talking with other parents about their situation

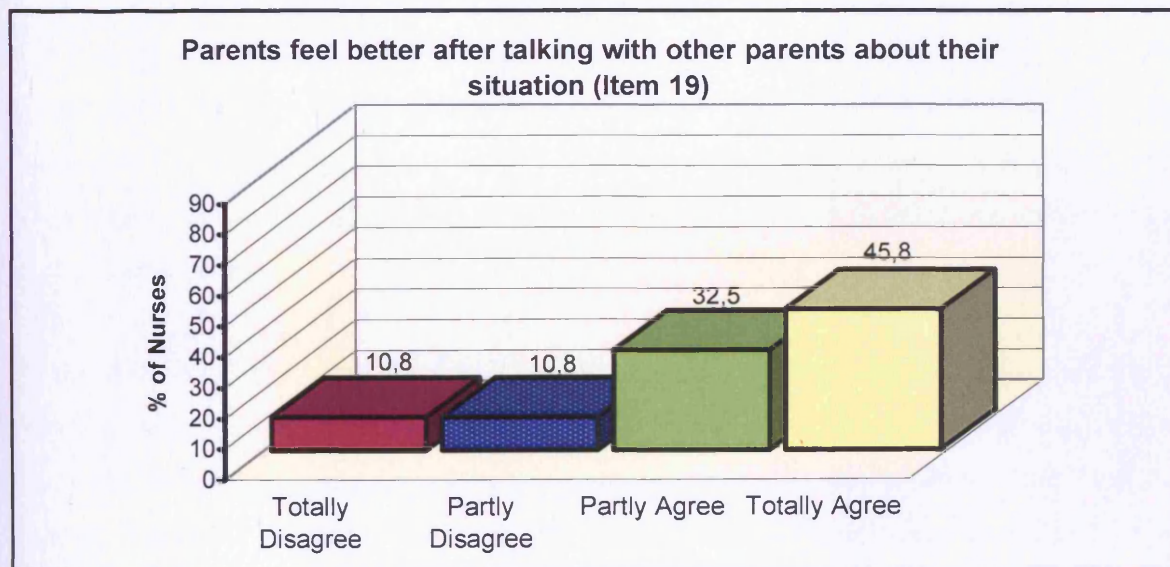


Figure 44. Nurses' Responses - Parents feel better after talking with other parents about their situation

Item 19

The majority of parents agreed that (n=99) they felt better after talking with other parents who faced similar problems and the majority of nurses agreed (n=61). This could be an indication that the support they reported that they had not received from the nurses was

5.6. Comparison of the parents' and the nurses' perceptions using Chi-square and Fisher's Exact Test

The chi-square test was used in order to compare responses of the two groups, the parents' and the nurses' perceptions of the role of the nurse in helping parents to cope with their children's chronic health problems. When carrying out the chi-square test, it was noted that if the expected frequency was found to be less than 5, a Fisher's exact test was needed according to Anastasi (1976). Thus, although the frequency value within some matrix cells were found to be less than 5, Dawson-Saunders and Trapp (1994) suggest the use of the Fisher's exact test when the expected frequency value is under 5. The Fisher's exact test was performed on the 6 items (questions) that were found in this study. It was interesting to note that similar values resulted with both tests for the probability value (p). In the table (Appendix IX) the asterisk represents the Fisher's exact test score and not the chi-square test score that is noted elsewhere.

The findings will be presented according to the concepts suggested by King's Theory of Goal Attainment (1981). It is of importance when the groups disagreed, suggesting a possible role conflict, but it was also important to present the issues where both groups agreed. In this way a better understanding of their interactions can be presented. These findings will be discussed in this chapter.

In the descriptive analysis, important information was obtained by counting how many nurses agreed with how many parents. In order to compare their answers the chi-square test was used. Since the questionnaire for each group was identical, the "slightly agree" and the "agree" columns were added together to form the "yes" or "agree" column, the same was done to form the "disagree" column, thus forming a two by two matrix. This was done, as suggested by Siegel and Castellan (1988), in order to produce the matrix needed to make a clearer comparison and interpretation of the response between the two groups.

The statistically significant differences found between the perceptions of the sample groups presented here were classified according to King's Individual, Interpersonal and Social Systems, followed by the non-statistically significant differences.

5.7. King's Individual System

5.7.1. Self and Body Image - Statistically Significant Findings

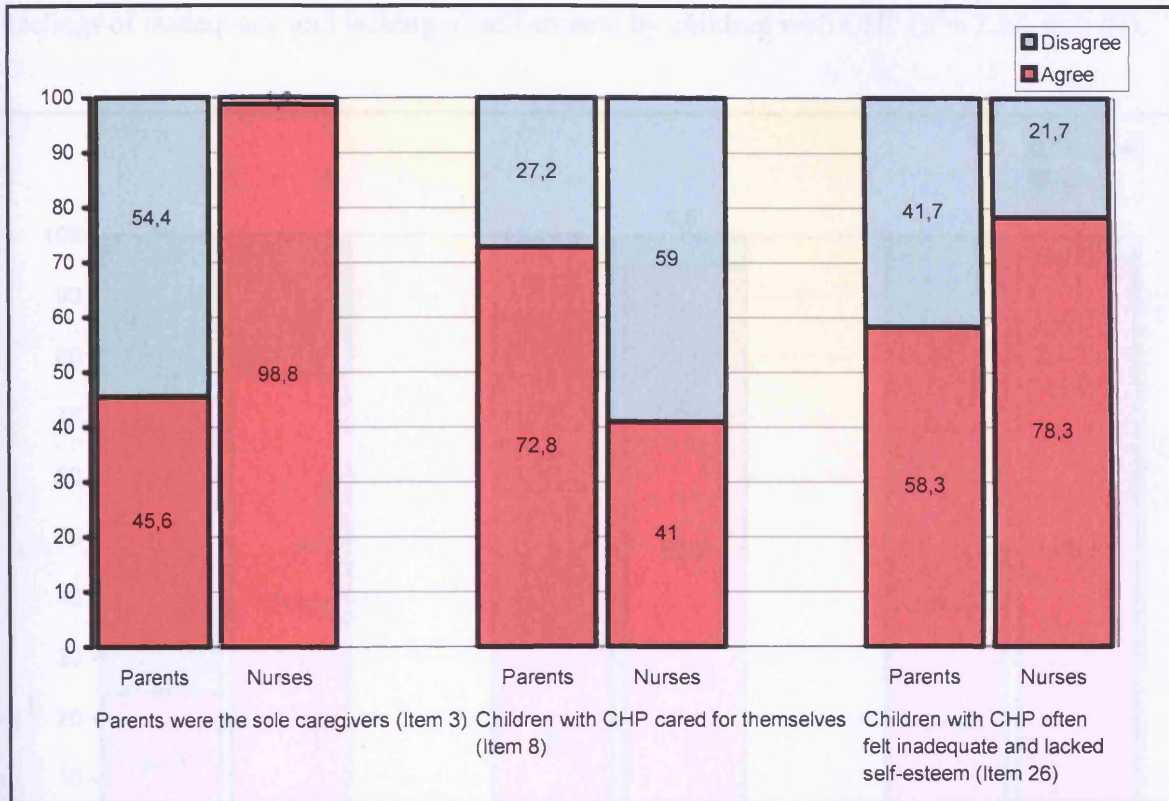


Figure 45. Items 3, 8, 26

Item 3

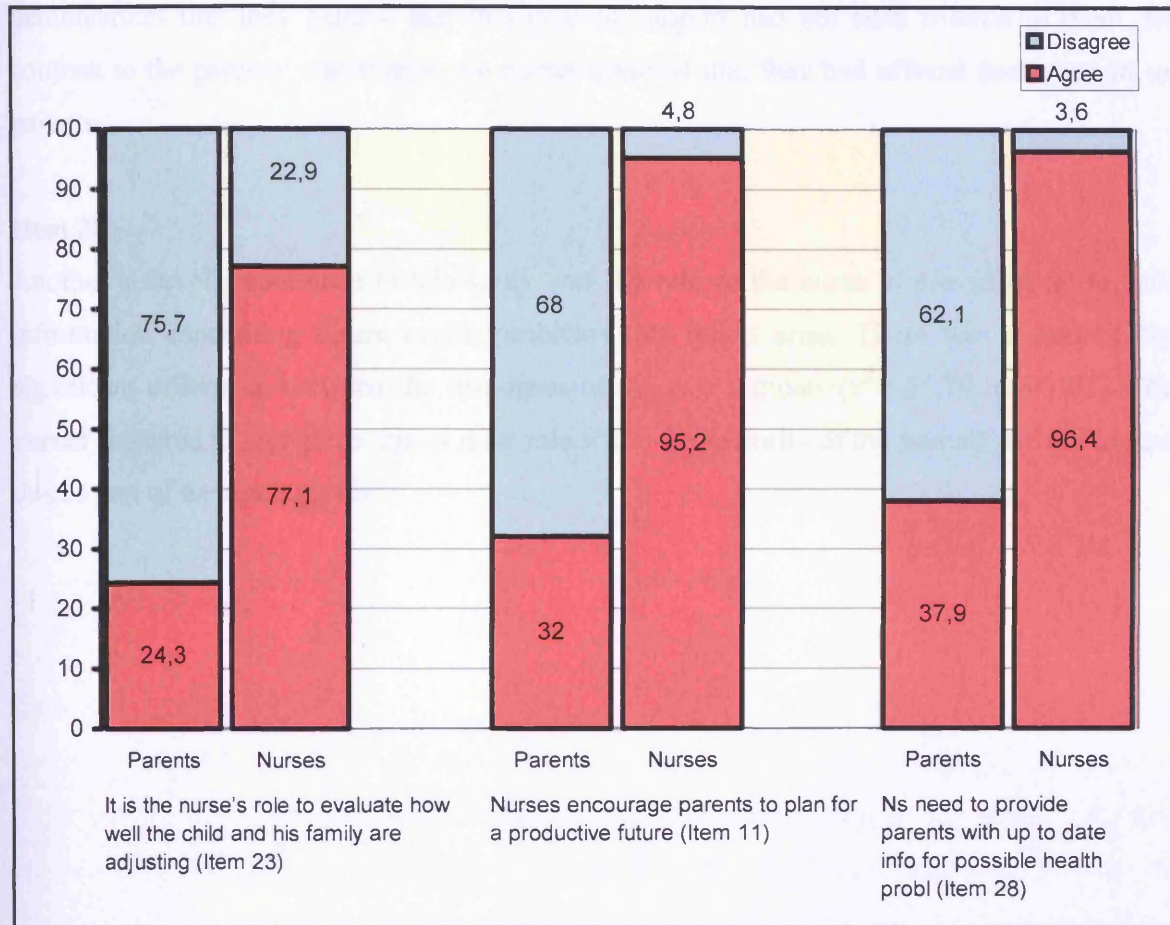
When both samples were asked if parents were the sole participants in the child's care a strong statistically significant difference was evident between the parents' and the nurses' responses ($\chi^2=58.65$, $p<0.001$). Almost all of the nurses believed that the parents were the sole participants in providing their child's care, while more than half of the parents disagreed and claimed they were not the only participants in their child's care.

Item 8

A statistically significant difference ($\chi^2= 17.93$, $p<0.001$) was found between the nurses' and the parents' responses concerning their belief that a child with CHP can successfully care for himself. The majority of the parents agreed with this statement in contrast to the nurses who disagreed.

Item 26

A statistically significant difference was found between the samples' responses concerning feelings of inadequacy and lacking of self-esteem by children with CHP ($\chi^2 = 7.51, p < 0.01$).



Figures 46. Items 23, 11, 28

Item 23

According to the literature, an important part of nursing rehabilitation is the role of the nurse in evaluating the adaptation level of the child and his parents. There was a statistically significant difference between the nurse and parent groups' responses ($\chi^2 = 49.32, p < 0.001$). The nurses identified this as one of their roles while the parents disagreed. Only a minority of the parents agreed that this is the nurse's role, while the majority of the nurses claimed this to be a part of their role.

Item 11

A statistically significant difference was found concerning the parents' and the nurses' perceptions about whether the nurses had offered encouragement in planning for their child's future ($\chi^2=73.88$, $p<0.001$). The majority of the parents disagreed with this statement which demonstrates that they believe that this type of support had not been offered to them. In contrast to the parents' statements, the nurses claimed that they had offered such support to parents.

Item 28

Another issue of importance to this study was the role of the nurse in providing up to date information concerning future health problems that might arise. There was a statistically significant difference between the responses of the two samples ($\chi^2= 65.79$, $p<0.001$). The nurses appeared to recognize this as their role while the majority of the parents did not expect this as part of the nursing role.

5.7.2. Self and Body Image - Non-Statistically Significant Findings

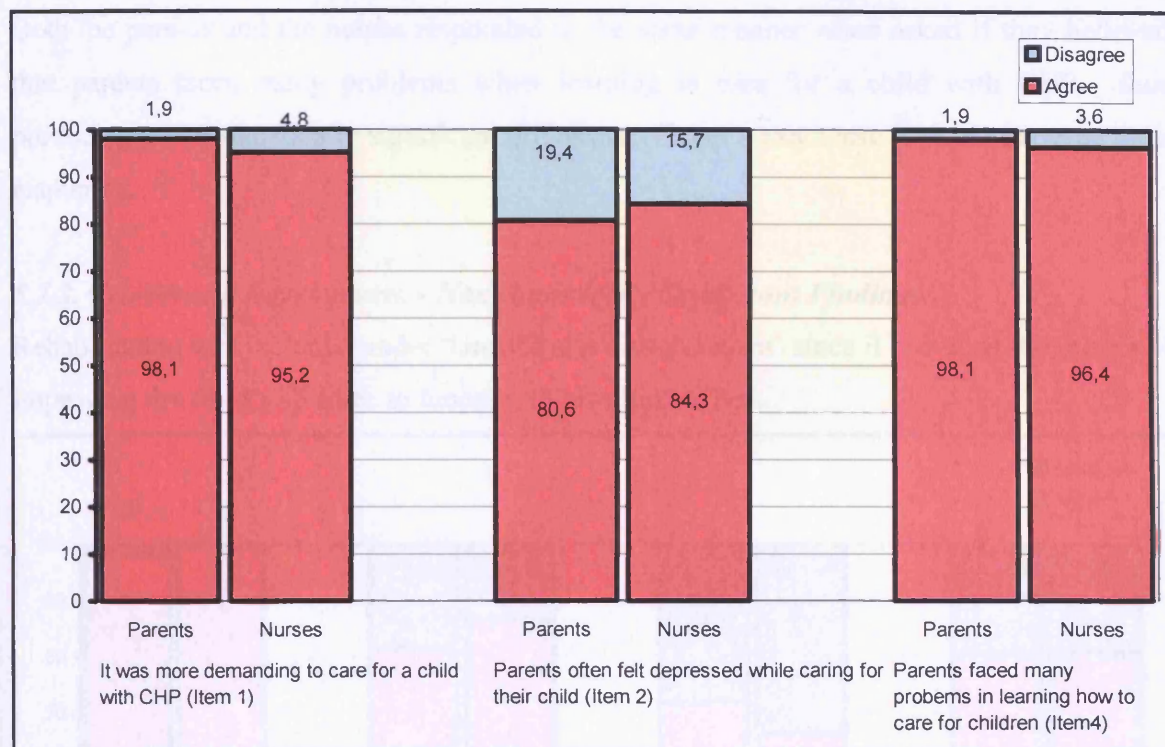


Figure 47. Items 1, 2, 4

Item 1

Items that referred to the “self”, such as item one, resulted in a non-statistically significant difference, ($p > 0.05$) based on the Fisher’s exact test, between the parents’ and the nurses’ responses. A large number of the sample of both parents ($n=101$) and nurses ($n=79$) agreed that it is more demanding to care for a child with CHP or disabilities than caring for a healthy child. With this question the nurses’ responses illustrated that they understood the complex and difficult situation that the parents were in.

Item 2

When parents and nurses were asked if it is depressing to care for a child with CHP, a non-statistically significant difference ($\chi^2=0.22$, $p > 0.05$) was evident from their responses. The majority of both the parents (80.6%, $n=83$) as well as the nurses (84.3%, $n=70$) agreed that it is often depressing to care for such children.

Item 4

Both the parents and the nurses responded in the same manner when asked if they believed that parents faced many problems when learning to care for a child with CHP, thus producing a non-statistically significant difference (Fisher's exact test: $p > 0.05$) between their responses.

5.7.3. Growth and Development - Non-Statistically Significant Findings

Rehabilitation was included under 'Growth and Development' since it provided the means of improving the child's abilities to function to his ultimate best.

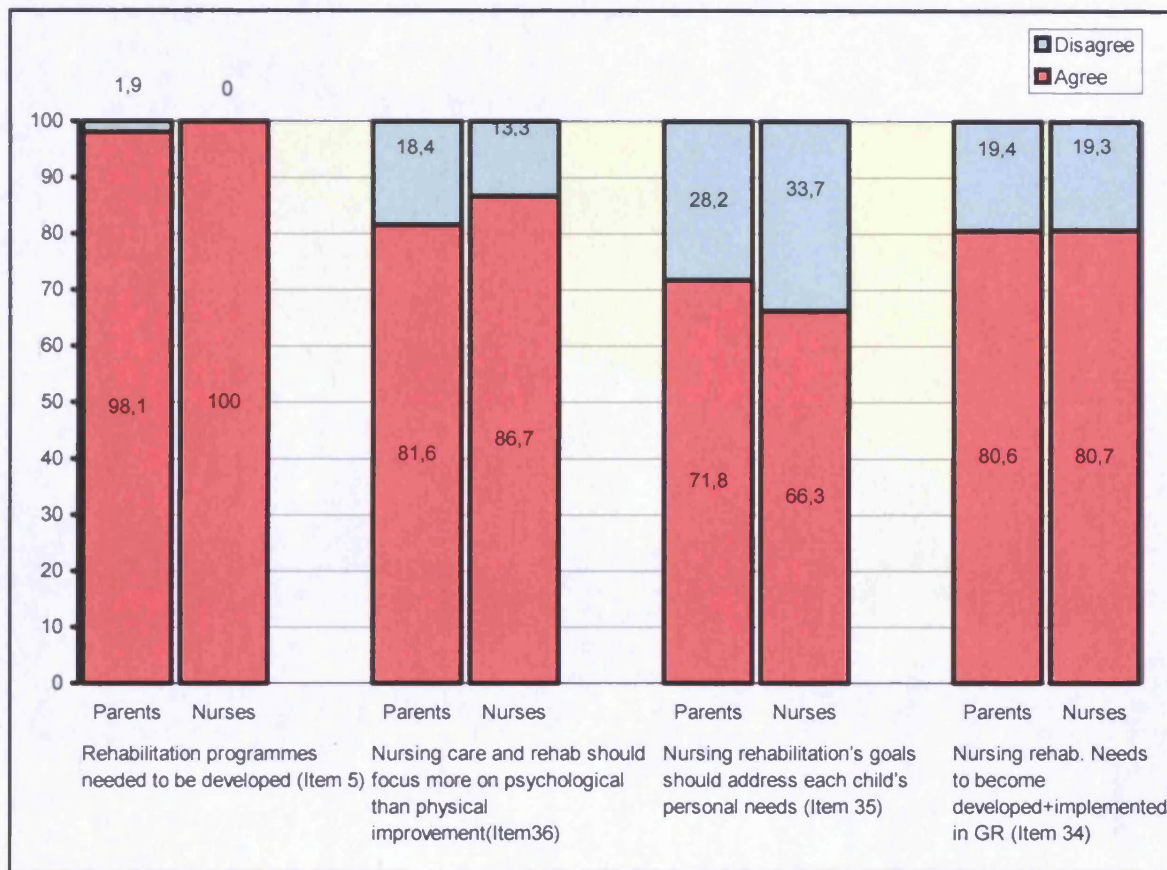


Figure 48. Items 5, 36, 35, 34

Item 5

All nurses and almost all parents agreed that rehabilitation programmes should be developed for children with CHP, thus producing a non-statistically significant difference in their responses (Fishers exact test: $p > 0.05$).

Item 36

Also, a non-statistically significant difference was found in the samples' responses concerning the need for the focus of nursing rehabilitation to be on psychological rather than physical improvements ($\chi^2 = 0.57, p > 0.05$). The responses of the nurses and the parents found both samples agreeing with this statement.

Item 35

A non-statistically significant difference was found in the samples' responses concerning their belief that nursing rehabilitation should be based on each child's personal needs ($\chi^2 = 0.44, p > 0.05$).

Item 34

In the same fashion, both nurses and parents agreed that nursing rehabilitation should become better developed and implemented in Greece, thus, resulting in a non-statistically significant difference ($\chi^2 = 0.001, p > 0.05$).

5.8. King's Interpersonal System

5.8.1. Nurse's role - Statistically Significant Findings

Questions concerning if nurses had undertaken their role of providing emotional support and encouragement met with disagreements between the two groups. The nurses felt to a greater degree that they had offered encouragement, while the parents felt this was not so.

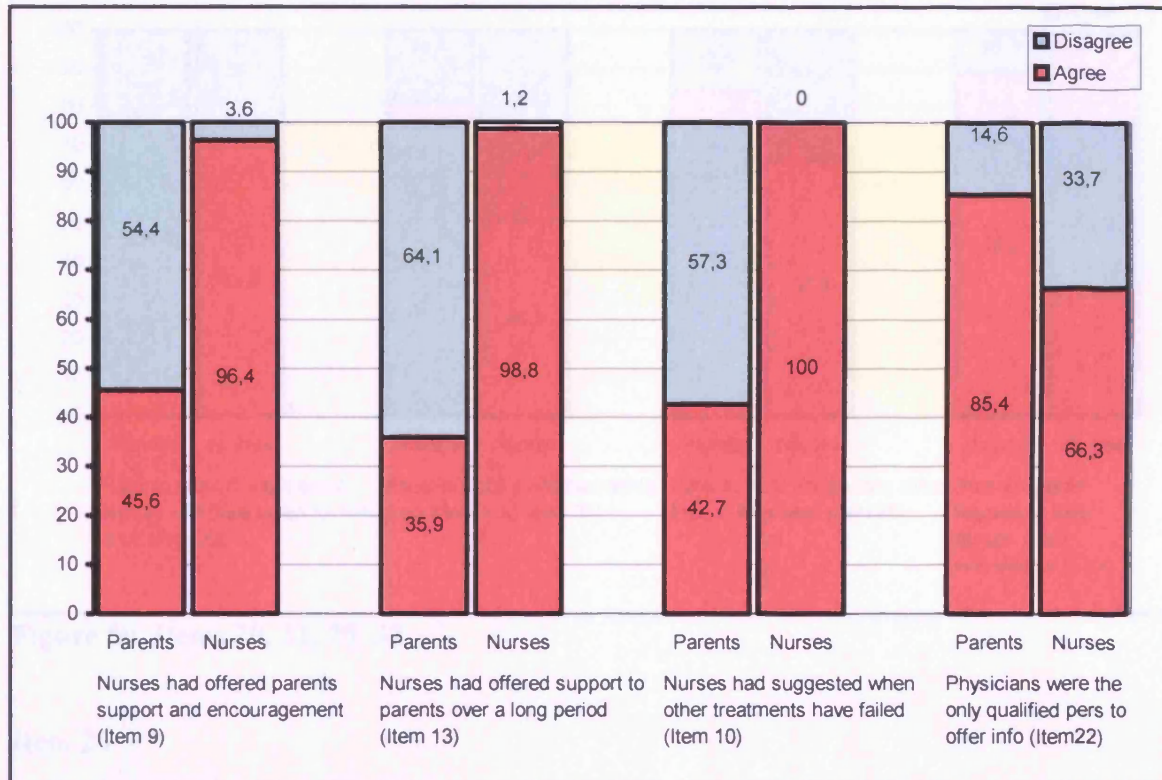


Figure 49. Items 9, 13, 10, 22

Items 9, 13, 10, 22

There was a statistically significant difference between the responses of whether nurses had offered support at all ($\chi^2= 52.35, p<0.001$), or whether or not they had offered support over a long period of time ($\chi^2= 76.13, p<0.001$). Also, a statistically significant difference was found between the nurses' and the parents' perceptions whether or not nurses had offered other treatment regimes when one method failed ($\chi^2= 67.01, p<0.001$). In all the above instances the majority of the nurses felt they had provided support while the majority of the parents disagreed.

Item 22

A statistically significant difference was found when the groups were asked if they believed that physicians were the only qualified persons to offer information to parents concerning their child's condition ($\chi^2= 8.46, p<0.01$). The majority of both samples agreed with this item, however, there was a higher level of agreement among the parents.

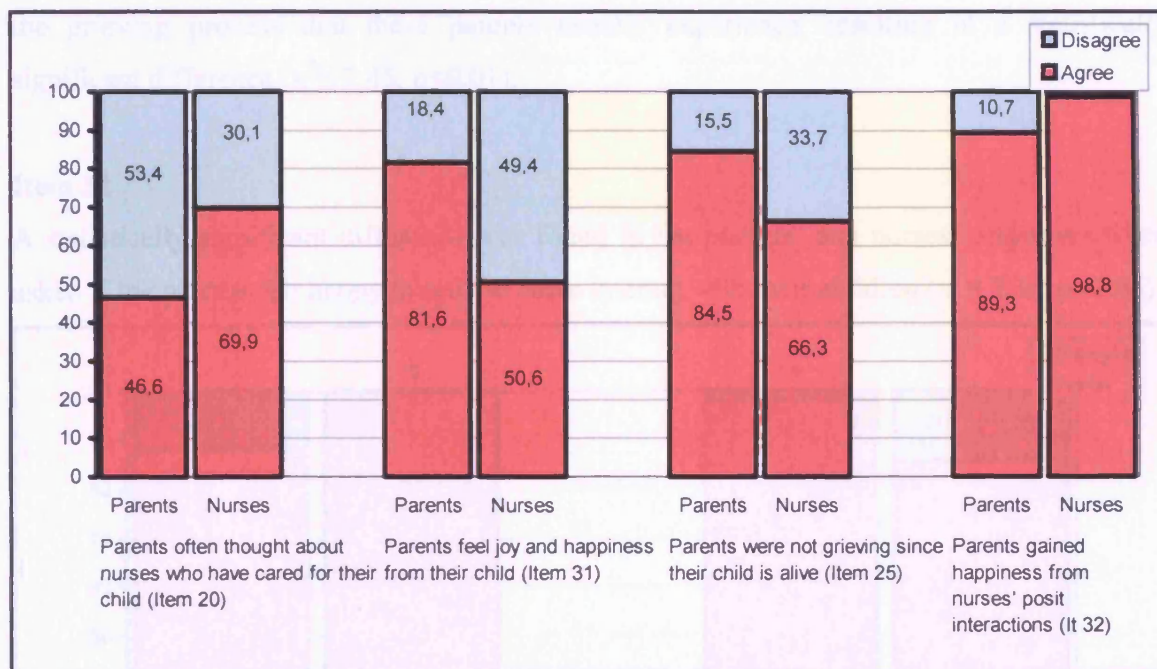


Figure 50. Items 20, 31, 25, 32

Item 20

When nurses were asked if parents thought about nurses who have cared for their child, they agreed. However, when the parents were asked the same questions, their opinions were divided, thus, producing a statistically significant difference between the two sample groups' responses ($\chi^2= 9.23, p<0.01$).

Item 31

It appeared that nurses may not understand that parents do not experience only sorrow and depression but often experience joy and happiness from their child. This was seen in this study when nurses and parents were asked their perceptions of whether parents derive joy from their ill child, a statistically significant difference was found ($\chi^2= 18.76, p<0.001$). Thus

the majority of the parents' sample agreed while only half of the nurses' sample agreed with the above statement.

Item 25

It appeared that the majority of the parents and two-thirds of the nurses did not understand the grieving process that these parents usually experience, resulting in a statistically significant difference ($\chi^2= 7.45, p<0.01$).

Item 32

A statistically significant difference was found in the parents' and nurses' responses when asked if the parents felt happy to see the nurse interact with their children ($\chi^2= 5.36, p<0.05$).

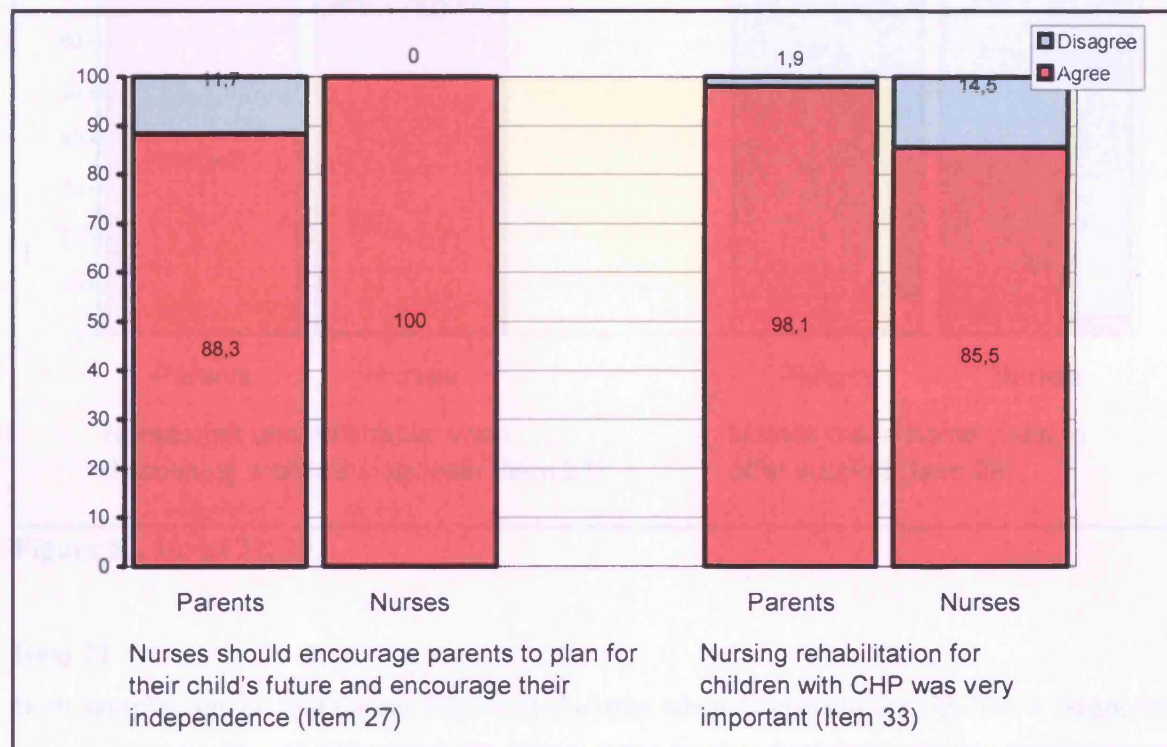


Figure 51. Items 27, 33

Item 27

A statistically significant difference was found between the parents' and the nurses' responses concerning their agreement that nurses should encourage parents to make future plans for children with CHP ($\chi^2= 8.5, p<0.01$).

Item 33

However, when asked if nursing rehabilitation was important for children with CHP the parents and nurses responses resulted in a statistically significant difference ($\chi^2= 8.62$, $p<0.01$).

5.8.2. Nurse's Role- Perception of Support - Non-Statistically Significant Findings

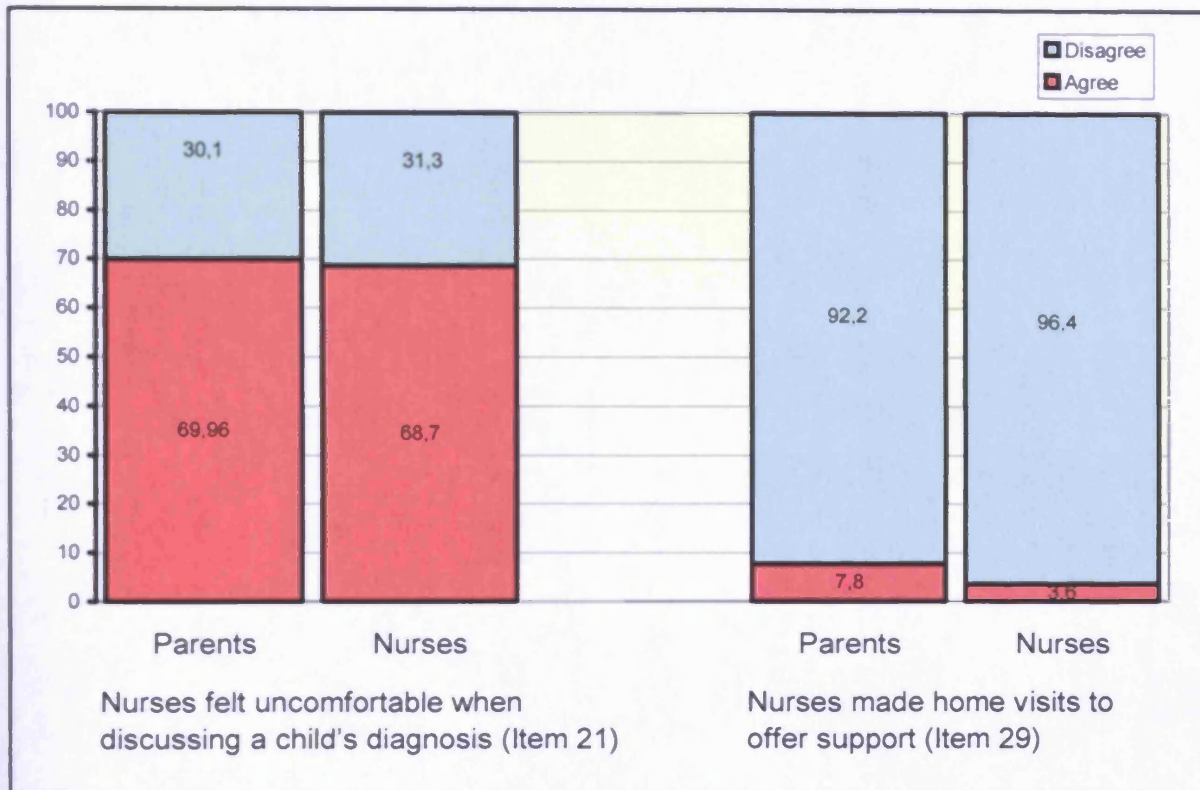


Figure 52. Items 21, 29

Item 21

Both samples agreed that nurses felt uncomfortable when discussing the children's diagnoses ($\chi^2= 0.03$, $p>0.05$, non-statistically significant difference).

Item 29

There is a non-statistically significant difference in the parent's and nurse's responses as to whether support was offered by nurses on home visits (Fisher's exact test $p>0.05$).

5.8.3. Communication Non-Statistically Significant Finding

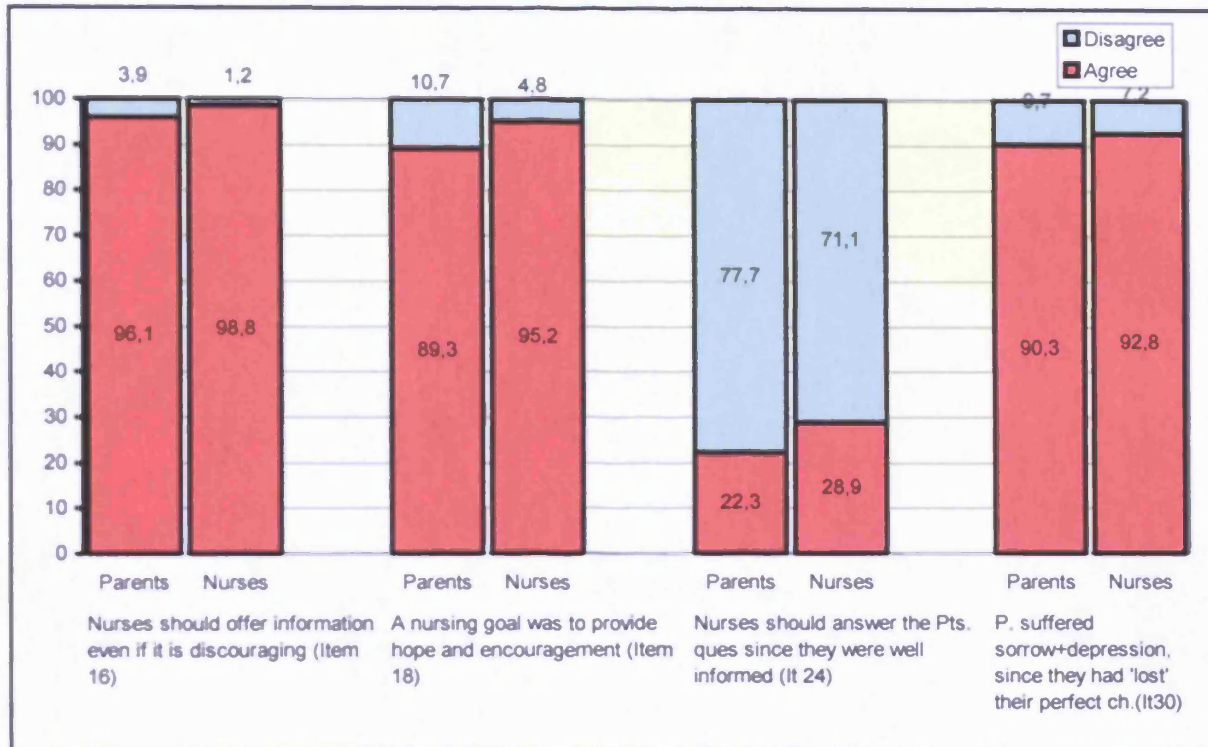


Figure 53. Items 16, 18, 24, 30

Item 16

Both parents and nurses agreed that information should be offered to parents even if it was discouraging (Fisher's exact test $p > 0.05$), thus, producing a non-statistically significant difference between their answers.

Item 18

Parents and nurses agreed that hope and encouragement were expected from nurses concerning the child's condition, thus, producing a non-statistically significant difference between their responses ($\chi^2 = 1.41, p > 0.05$).

Item 24

A non-statistically significant difference was found between the parents' and the nurses' beliefs that nurses should attempt to answer questions since they were well-enough informed ($\chi^2 = 0.74, p > 0.05$). Both the majority of the nurses and the parents disagree with this item suggesting that this was not a role the nurse should undertake.

Item 30

A non-statistically significant difference was found between the parents' and the nurses' perceptions concerning the belief that parents felt periods of sorrow and depression having felt the loss of their "perfect" child ($\chi^2 = 0.11$, $p > 0.05$). The majority of both samples agreed that such feelings were considered depression when the literature defines it as "chronic sorrow", which will be explicitly discussed in the following chapter.

5.9. King's Social System

5.9.1. Social System- Statistically Significant Findings

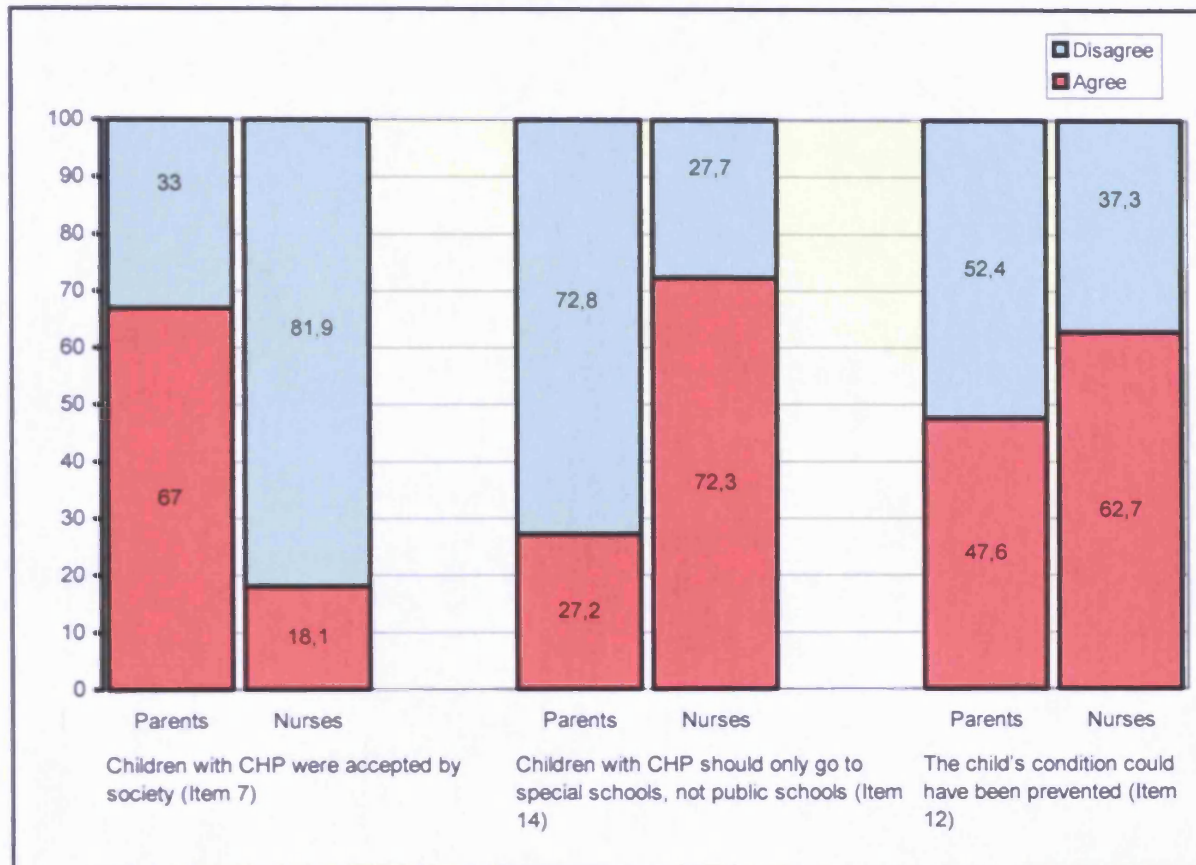


Figure 54. Items 7, 14, 12

Item 7

A statistically significant difference was found between the nurses' and parents' perceptions as to whether these children were accepted or not within the community ($\chi^2= 42.46$, $p<0.001$). The majority of the parents reported that they felt their child was accepted within the community yet the majority of the nurses felt the community did not accept them.

Item 14

These children needed to develop and to become as independent as possible, thus it was important which school these children attended since it was very vital to their future. There was a statistically significant difference between the perceptions of the groups which suggested that there possibly was a misunderstanding on the part of the nurses ($\chi^2= 35.72$,

p<0.001). They seemed unaware that parents preferred public schools if at all possible since this provided a better education, more social acceptance and even the possibility of university attendance.

Item 12

A borderline statistically significant difference was found when comparing the parents' and the nurses' perceptions concerning their belief if the child's condition could have been prevented ($\chi^2= 3.62, p\leq 0,05$). There were indications that two-thirds of the nurses agreed with this while almost fifty percent of the parents agreed.

5.9.2. Parent Support Groups-Statistically Significant Findings

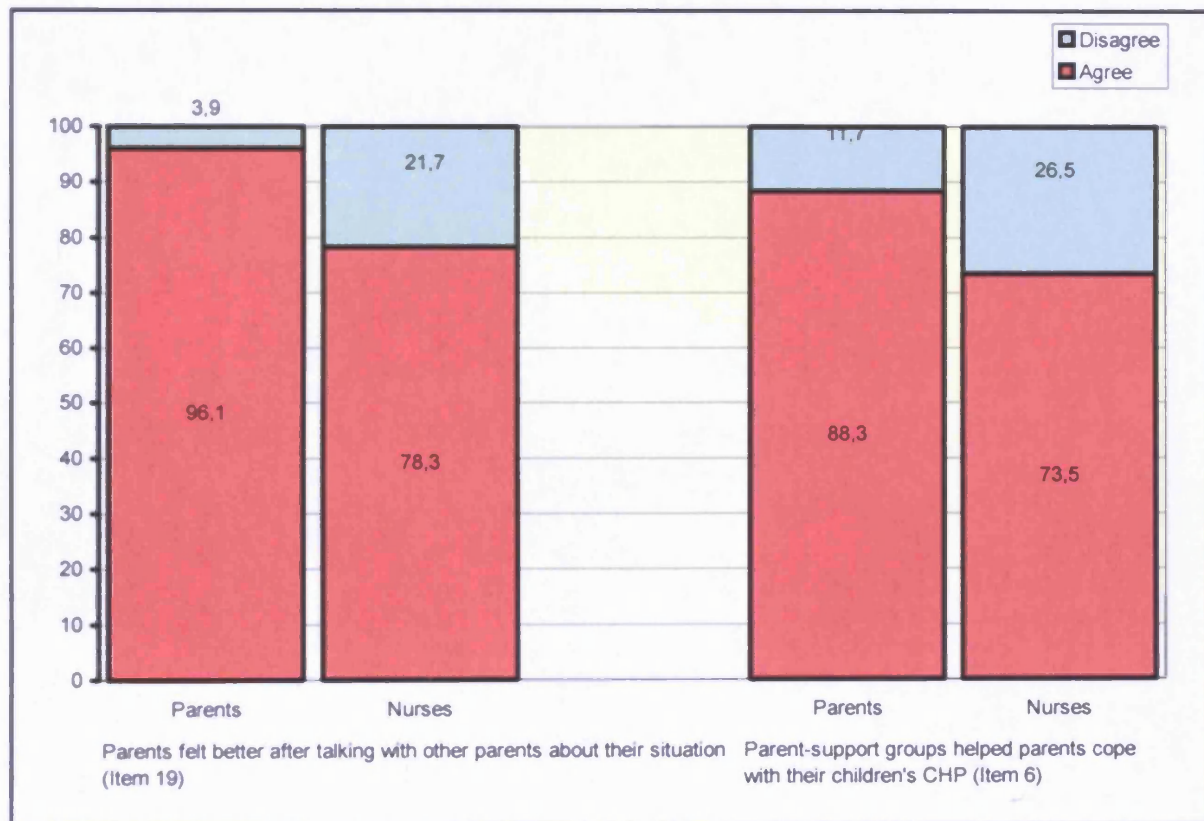


Figure 55. Items 19, 6

Item 19

A statistically significant difference was found in the parents' and nurses' opinions, since the nurses' opinions demonstrated a lack of understanding of the fact that the majority of parents reported that they felt better as a result of interacting with other parents ($\chi^2= 12.31, p<0.001$).

Item 6

A statistically significant difference was found between the parents' and the nurses' responses concerning the perception that parent-support groups brought about positive results in helping parents cope with their child's health problem ($\chi^2= 5.83, p<0.05$). Both samples supported this belief. However, a larger percentage of the parents agreed.

5.9.3. Community- Social Stigma Non-Statistically Significant Findings

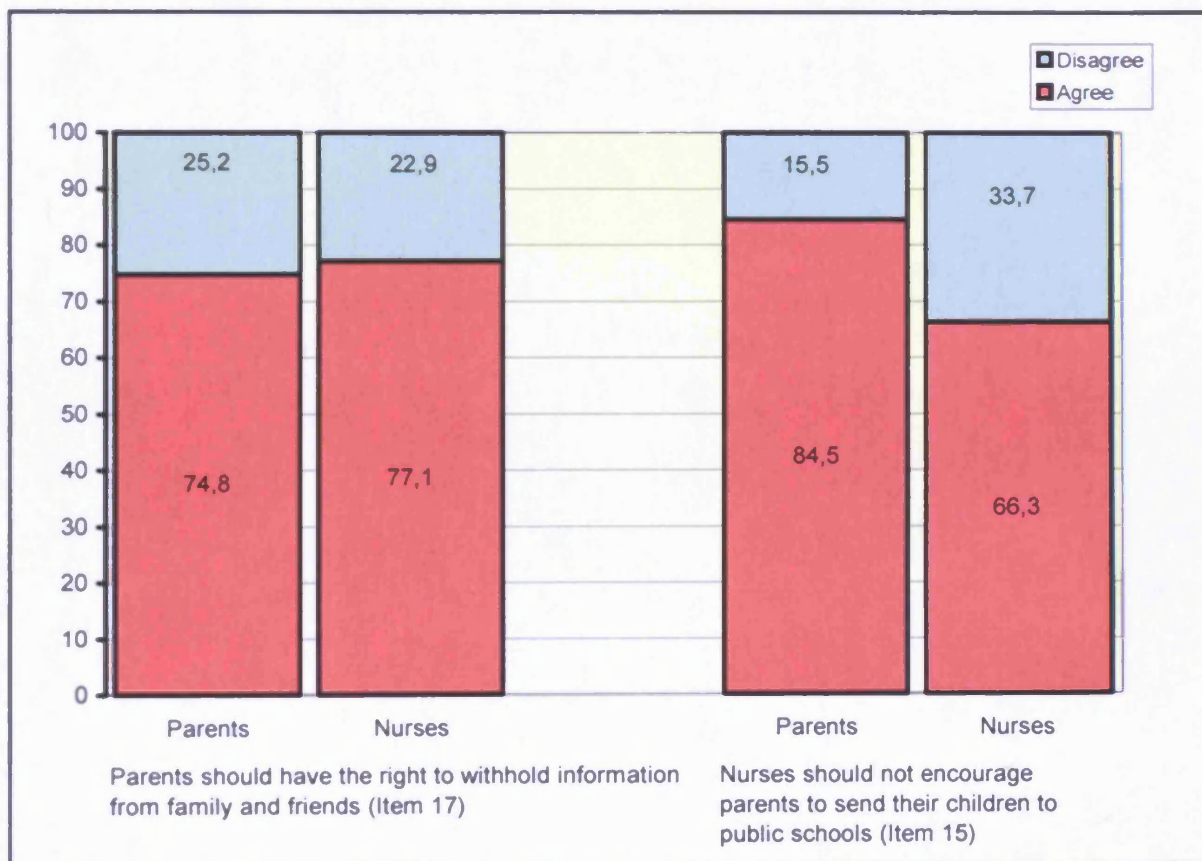


Figure 56. Items 17, 15

Item 17

A non-statistically significant difference was found concerning the parents' rights to withhold information about their child's condition from family and friends ($\chi^2 = 0.04$, $p > 0.05$).

Item 15

A non-statistically significant difference was found between the parents' and the nurses' responses concerning the encouragement offered by nurses to send their children to public school. Nurses agreed that they had not offered such encouragement, and parents agreed that they had not been offered such encouragement (Fisher's exact test: $p > 0.05$).

These were the important statistical findings that reinforced the descriptive and qualitative findings that will be discussed later. The presentation of the non-statistically significant findings of the chi-squared analysis and the Fisher's exact were presented, since they offered an insight to the areas of agreement between the nurses' and the parents' perceptions.

5.10. Summary

Based on the decisions made in the Method chapter, the quantitative portion of the study was carried out. This chapter began with the description of the samples. Included were the graphs of the most significant responses to the items. Then the statistically significant differences of the parents' and the nurses' perceptions using either chi squared or Fisher's exact tests were presented. The presentations of the non-statistically significant findings were also presented since they offered an insight into the areas of agreement between the nurses' and the parents' perceptions.

In the following chapter, all of the findings and results from both portions were combined in order to discuss them with the findings of other researchers as found in the relevant literature.

Chapter VI. Discussion

In the previous two chapters the findings of both research methods were presented separately. In this chapter, these results will be combined along with the relevant literature to determine the results of this study in terms of agreement or non-agreement with other studies. Results that contradict findings of other studies could suggest the need for further research to resolve such contradictions.

6.1. Introduction

King (1981) suggested that the importance of nurses offering psychological support is so that they can attain goals which assist patients in their coping abilities. Through these coping abilities parents of children with CHP would be better able to deal with all aspects of their children's care. She suggested that in order to attain transactions that lead to satisfactory and effective nursing care there needed to be an agreement between the nurse's and the parents' perceptions of the role of the nurse. For this reason, this study included a comparison of the perceptions of the two sample groups, parents and nurses, concerning the nurse's role in order to explore possible role conflicts. A discussion of the results from the descriptive and the statistical analysis of the 186 questionnaires, along with the qualitative findings of the 60 interviews, and the relevant literature were combined and presented here.

Lincoln and Guba (1985) suggest the rigour in a qualitative research is achieved through the concepts of credibility, transferability, confirmability and dependability. Credibility of this study's research methods and subsequent findings was achieved through numerous strategies incorporated within the data collection and analysis. A common type of data collection technique included prolonged engagement which was accomplished by the researcher interviewing the same person for an extended period of time. Another strategy for establishing credibility was through data and methodological triangulation. This was the reason that both nurses and parents were included. In using the two methods, the qualitative and quantitative paradigms, both "soft" and "hard" research methods were incorporated.

The goal of the qualitative portion of this study was not generalisability. Instead, transferability is used to judge the extent to which these findings can be applied to other contexts. Specific strategies were used to achieve transferability such as thick descriptions and purposive sampling. The thick descriptions were richly described data that provided enough information to judge the themes and categories of the study. In this way, they provided enough information to judge the appropriateness of applying these findings to other settings. Confirmability and dependability of the research process was achieved through the researcher's audit trail. This was accomplished by specific documentation in the researcher's journal and by the original data, along with the earlier data interpretation or analysis. A decision trail, along with an audit trail of a sample of how one theme was developed, can be found in Appendix X.

Descriptive phenomenology was used since it was important to analyse the qualitative data in such a way as to preserve the meanings that the participants gave to their original "lived experiences" and to present them in such a way that would allow others to understand their meanings. These interviews presented possible role incongruence and added insight into possible causes for them. This information would have been unattainable by conducting only a quantitative study.

In the quantitative portion of the study some topics were identified which illustrated a difference between the parents' and the nurses' perceptions as seen in the descriptive analysis and the chi-square or Fisher's exact test. A discussion of the differences along with the appropriate literature will be presented.

Every parent reported that they had experienced shock when they realised that their child had an altered body image, either at birth or later during the child's life. In order to understand the impact of body image alterations on the Greek family, a little insight into the views of their society needs to be included.

The social hierarchy, as described by Groce and Zola (1993), divides members of society according to family's connections, education and wealth. This was apparent in the Greek society and influenced how the family accepted a less than perfect child. The sample of parents participating in this study were mostly high school graduates and of low-income families. According to Tripp-Reimer and Sorofman (1998), the poorer population knows that wealth is unattainable, but they realise that through educating their children the family would be able to obtain a higher social status. The hope for greater social status is lost to every member of the family when a child has an altered body image due to a CHP, thus, the family loses more than just a healthy child, but also a way of improving their life-style.

6.2. King's Personal System

6.2.1. Self

It appeared that most nurses were not aware of the parent's role in caring for their child since there were disagreements between the nurses' and the parents' perceptions concerning whether these children cared for themselves and if the parents were the sole carers for these children. The majority of the nurses (98.8%) believed that the parents cared for their children alone, while in this sample less than half of the parents (45.6%) were the total caregivers. The chi-square test suggested a strong statistically significant difference ($\chi^2 = 58.65$, $p < 0.001$) in perceptions between the sample groups. This perhaps was indicative that within the Greek culture the extended family participated in providing care for these children.

Evidenced by the parents' interviews, even though it was reported that there was a stigma, the other family members were usually willing to participate in caring for these children. However, depending on the diagnosis and how much care was involved, parents often did not feel comfortable leaving their child with unskilled family members. Lugton (1997) suggested that all family members needed support. As described by Tripp-Reimer and Sorofman (1998), the Greek family consists of the parents, the children and the extended family, which include aunts, uncles, cousins and grandparents, and there is a

great expression of respect, concern and loyalty among family members. Even “in-laws” are considered first-degree relatives, honour and shame are not only concerns for each family member but are a matter of concern for all family members. Elders are greatly respected within this community and participate fully in family activities.

Although many of the parents in this study reported that they often found support from other family members, the nurses were not so enthusiastic and complained that the families were often interfering in their nursing care because so many family members visited and stayed for a long time. Many nurses reported that family members were not always cooperative.

One of the questions (or items) was whether the parents found it more difficult to care for their child than for a healthy child. The Fisher’s exact test suggested a non-statistically significant difference in the perceptions between the sample groups. The majority of the two groups agreed that it was more demanding than caring for a healthy child, however, a few parents (1.9%) and nurses (4.8%) disagreed. During the interviews many mothers reported that it had become more demanding as their children grew and became more difficult to manage and to lift. One mother reported how she used to carry her immobile daughter around but now the child was 13 years old and weighed too much and the mother found it more difficult physically to care for her child.

Most nurses (92.8%) understood that parents often had feelings of depression while caring for their child, however, only 1% of the parents disagreed. A non-statistically significant difference was evident from the responses of both groups. The literature found that parents seemed to adjust although they had various periods that brought back their feelings of sadness that their child was missing out on a normal life as was described by Meleski (2002).

Hatton *et al.* (1995) found similar results in their qualitative study of parents’ perceptions of caring for an infant or toddler with diabetes. These parents reported feelings of time-bound grief as described by Kubler-Ross (1970). They told how they became depressed

over losing their healthy child, the loss of their previous lifestyle and their lack of privacy as a couple. Some parents had to rearrange work schedules so they could be available more for their child, as seen with the couple as described in this study.

Parents in the Hatton *et al.* (1995) study and in this study reported the difficulty in being alone as a couple because they were afraid to leave their child with others. Some parents even mentioned that their life was so much sadder than it used to be while other couples worked hard at “pretending” that they led a normal life. The use of qualitative research provided vivid descriptions to both of these studies that would have been lost by carrying out only a quantitative study. In this study, there were many examples of parents who expressed their feelings of being depressed while caring for their child, but one that could be included here was Frank’s mother. She admitted she felt depressed when Frank expressed his anger that he had to live paralysed in a wheel chair while he watched his brothers and sister live an active life. Other examples were the priest and his wife watching two of their once-normal children becoming slowly paralysed and unable to speak, and the parents with their young son with diabetes.

6.2.2. Self-esteem

In the descriptive analysis the majority of the nurses (78.3%) agreed that these children lacked self-confidence and self-esteem, but only about two-thirds of the parents (58.3%) agreed. In the chi square test ($\chi^2=7.51$, $p<0.01$), a statistically significant difference was evident from the responses of both groups. The literature had found that children with CHP often felt more inadequate as compared to a control group, such as in studies by Ell and Reardon (1990), Sapountzi-Krepia (1997), and Camfield *et al.* (2001). Camfield *et al.* (2001) studied 114 children who suffered from epilepsy and reported lower self-esteem in those children whose illnesses were most severe. Sapountzi-Krepia *et al.* (2001) found in their study Greek study of 150 secondary school children that wearing a scoliosis brace resulted in these children having a lower self-esteem than the control group.

However, other studies had found this was not the case, such as Yan *et al.* (1999) and Noll *et al.* (2000). A study carried out by Yan *et al.* (1999) showed that the majority of hospitalised Chinese school aged children with chronic illnesses had an average level of self-esteem, which was in agreement with Noll *et al.*'s (2000) study of children with juvenile rheumatoid arthritis.

In the qualitative portion of this study, the interviews resulted in a variety of findings. Many of the parents of children with non-obvious illnesses, such as asthma and diabetes, reported that their children had normal self-confidence. It was pointed out in the literature that children with supportive adults had a more positive body image (Camfield *et al.*, 2001; Carson and Heiber, 2001), and since the Greek parents interviewed appeared to be very supportive this could perhaps be the reason why they felt that their children had normal self-esteem. However, there was always the possibility that the combination of children with such a wide variety of diagnoses may have influenced this outcome. Thus, it appeared that too many variables were involved to reach any conclusions and this subject warranted a study of its' own.

6.2.3. Nurse's role in nursing rehabilitation

The findings of this study suggested that the entire parent sample had experienced difficult periods, and most stated that in the beginning they could not begin to understand how they were going to get through those periods. The altered body images affected the child's life, the family's life and their life within the community. During the interviews many parents reported how they were unprepared to deal with such dramatic changes in their life. Salter (1988), Deusen (1993), Jamieson (1996) and Chen *et al.* (2002) suggested that this was common since most people have difficulties in adapting to altered body image.

In the interviews the majority of both samples expected rehabilitation such as physical therapy and speech therapy. Most of the participants were unaware that in "nursing rehabilitation" the nurse planned the rehabilitation program that involved other health professionals, but was guided by nurses. The majority of nurses were uninformed that

nursing rehabilitation was a special practice area for nurses. They were unaware that nurses could diagnose actual or potential health problems that resulted from altered body image, and that they could assist in restoring, maintaining and promoting optimal health to their patients.

The majority of both groups (80.7%) agreed that nursing rehabilitation was important. The parents' and nurses' responses resulted in a statistically significant difference ($\chi^2 = 8.62, p < 0.01$). The majority of parents (81.6%) and nurses (86.7%) agreed upon a need for nursing rehabilitation to have more emphasis on psychological needs rather than only the physical problems as it was at present. These responses produced a non-statistically significant difference ($\chi^2 = 0.57, p > 0.05$). A few parents suggested that there was a need for public education to explain the importance of nursing rehabilitation. However, in the interviews there were parents that reported satisfaction since they claimed that some nurses had adapted nursing interventions according to their child's needs and abilities. They complained that not enough emphasis was being given to the psychological aspect of their child's rehabilitation.

Most parents claimed that rehabilitation in the physical sense was being offered to a certain degree. These parents felt that rehabilitation was focused too much on improving physical functioning, which was not always possible. The parents of children with permanent disabilities or progressive degenerative conditions found that the importance placed on physical improvement created many disappointments since their children's conditions became worse, not better. In agreement were Amvrazi (2004) and Vardakastanis and Chatzipetrou (2003), they pointed out that some disabled Greeks believed rehabilitation was important but should also address their emotional and psychological needs and include work and vocational aspects of their care, which was not usually being done at present. Sapountzi-Krepia *et al.* (2001) argued that in Greece changes in basic nursing education were needed in order to identify rehabilitation as one of the nurse's duties. They suggested that this would benefit children and families while adding a new dimension to nursing.

Statistically significant differences ($\chi^2=49.32$, $p<0.001$) were found concerning the role of the nurse as evaluator of how well the child and his family were adjusting to the altered body image which is considered an important role of the rehabilitation nurse. Most nurses (77.1%) recognised this as their role, but only 23.3% of the parents felt that nurses should undertake this role, suggesting a role conflict which could interfere with parents cooperating with the nurses.

However, current rehabilitation practices were often considered inadequate since most parents felt their child's on-going needs were not being met. Many of these parents reported that they needed health promotion knowledge and rehabilitation in order to improve their children's quality of life and to encourage their children's self-care and independence. When the parents were asked how nursing rehabilitation could be better developed in Greece, many parents responded that they felt nurses needed to become better informed and more involved. Some nurses agreed and had expressed their feelings that their education was inadequate concerning chronic illnesses and disabilities. This was in agreement with Nolan and Nolan's (1999) study of the nursing curricula in the UK which found that nurses had not received enough courses on these subjects.

6.2.4. Perceptions of Nurse's Role in Offering Information

Thus, it seems that the role of the physician and nurse are important when discussing the findings of this study. They help to explain the results that physicians were seen as in agreement with Parsons (1951) by both the majority of parents and nurses. Both groups seemed to be aware that they were dominant over the nursing profession with the agreement to be so by most of the nurses. It appeared that the majority of both samples saw physicians as affectively neutral, showing no emotion of sentimental ties but universal in their approach. Both groups seemed to want them to use an objective scientific approach no matter whom they were treating. They were also in agreement that their opinions were needed and respected because of their achievements. The physicians' role was concentrated on achieving since they spent many years of studying in order to gain their right to practice. Porter (1998) claims the exception to Parsons' (1951) instrumental role of doctoring is that of "collective orientation". This means the doctor

should perform public service and not be interested in profit. Porter argues that if this were true how come they have such status and earning ability. The functionalists believe that this is so because of their important functional position and skills needed by our society.

Groce and Zola (1993) emphasised that up-to-date information must be provided, unfortunately, some nurses reported that they had not evaluated how the information was processed and implemented by the parents. Although all of the nurses (98.8%) felt that they provided much information, more than half of the parents disagreed (64.1%). The parents' and nurses' responses resulted in a statistically significant difference ($\chi^2=52.35$, $p<0.001$). A few nurses felt the possible explanation for this difference in perceptions was that the parents might have misinterpreted or rejected the support that they had offered. However, a few nurses admitted that they had not used good counselling skills such as asking the parents questions and listening to their replies.

Only about a third of the parents (32%) claimed that nurses had offered them encouragement to plan for their child's future, yet most of the nurses (96.2%) reported that they had offered such encouragement. The parents' and nurses' responses resulted in a statistically significant difference ($\chi^2=73.88$, $p<0.001$). In discussing whether parents should be informed of future problems that their child might encounter, there was an agreement between the two samples, nurses felt (98.8%) that they should offer this information and most parents (96.1 %) agreed. This agreement between the groups was found in the descriptive analysis and the interviews. The Fisher's exact test suggested a non-statistically significant difference in the perceptions between the sample groups (Fisher's exact test, $p>0.05$).

In the interviews, the nurses reported that they had often attempted to provide parents with information, but they questioned whether or not these parents wished to accept their information. In the descriptive analysis it was found that only 37.9% of the parents responded that they wanted the nurses to provide them with information, and 96.4% of

the nurses felt this was their role. The parents' and nurses' responses resulted in a statistically significant difference ($\chi^2= 65.79, p<0.001$).

The findings of this study suggest that the majority of nurses and parents, all being members of the same society, respect the medical model and view the physicians as having more knowledge and the nurse as being subservient and not as trusted to offer important information and advise, as Parsons (1951) identified in his role patterns. However, not all nurses and parents agreed with these roles. As discussed in the qualitative portion of the study, it depended on the parents' experiences throughout their life as to how much they respected nurses. Some had had very positive experiences with nurses who had not been "handmaidens" to the physicians but had offered professional nursing care.

It appears that parents approached health care professionals because they needed relief. They searched for expertise such as knowledge, skills, training, and experience that their desperation allowed them to hope existed with them. However, in addition to being competent, the health care professional needed to be viewed as trustworthy. Caring providers such as nurses have been characterized as exhibiting universal attributes of genuineness, love, unconditional acceptance and positive regard. Parents explained that their trust was sometimes compromised when they went to the nurse expecting to be advised on the expert handling of a problem and were met with the suggestion of "go and ask your doctor", in this way nurses helped re-enforce the medical model. This advice would be perceived by the parent as the nurse not understanding or as not having the knowledge that they needed to solve the parents' problems, resulting in lack of trust. This occurred quite often according to the reports from the parents, but also from the nurses, resulting in a negative response to nurses when some of them felt confident and offered information.

Parents claimed (85.4%) that only physicians were qualified to offer information, and 86.3% of the nurses agreed. The parents' and nurses' responses resulted in a statistically significant difference ($\chi^2= 8.46, p<0.01$). Many nurses (96.4%) reported that they had

offered support to these parents but they felt that many times parents rejected their support. In the interviews it was often reported by the nurses that parents wanted just loving attention given to their children and nursing skill techniques to be offered, which they considered the "art" of nursing. As one nurse stated, "*many parents consider nursing to be an art and not a science.*" Although many parents did not want information from nurses, 89.3% admitted that they did want attention from the nurses for their children and 98.8% of the nurses understood this need. The parents' and nurses' responses resulted in a statistically significant difference ($\chi^2 = 5.36, p < 0.05$). In the interviews some parents explained that when they saw nurses interacting with their children it encouraged them to believe that in the future their children would receive the same support within the community setting. They reported that this offered them encouragement for their children's future.

In the quantitative portion of the study, most parents (96.1%) reported that they wanted to receive information, even if it was discouraging, and 96.8% of the nurses agreed. This showed a non-statistically significant difference (Fisher's exact test $p > 0.05$). During the interviews the parents clarified this by saying that even though it was painful to hear and to think about bad news, they needed this information in order to develop future plans. Many explained that the lack of information made their problems worse since information was necessary for them to make decisions based on facts. They reported that as time passed and they became more informed about various topics, they realized that they had often made incorrect choices for their child due to lack of information. One parent pointed out that,

"Nurses need to realise that parents do not want information out of curiosity, but because it affects their decision-making process."

Thus, they needed to know the truth even if it was unpleasant.

Some parents reported that they had missed out on services since the health care professionals had not informed them that they were available. Similar findings were

described in a study by Newacheck *et al.* (1998) who examined two groups and discovered that one group had received a high level of services while the second group had not received services due to lack of knowledge on the part of the parents.

A review of this study's demographic information concerning the parents demonstrated a high percentage of participants were grade school or high school graduates with low-income jobs. It must be remembered that some nurses at the community health centres had reported that the wealthier parents did not register their children at government operated health centres but sought out private physicians and hospitals. This was done to prevent calling attention to their children and their health conditions. As mentioned before, there was a stigma to all family members and it was suggested that these parents might be trying to avoid this stigma.

Newacheck *et al.* (1998) reported similar findings that families with low incomes were about one third more likely to have greater health needs than higher educated parents, and that children in single-parent families were 40% more likely. As in this study, chronic health conditions varied in their nature and severity and in their requirements for medical services. This study combined children with these varied diagnoses since Perrin *et al.* (1993) emphasised that there were many common factors involved although there were differences in each health condition. Some of these differences were the need for a variety of community and health professional services.

6.2.5. Parents' Fears

A majority of both parents (98.1%) and nurses (95.2%) agreed that caring for a child with a chronic illness involved an increased workload along with many fears for their child's life, as well as for his future. These findings produced a non-statistically significant difference between the parents' and the nurses' perceptions (Fisher's exact test $p > 0.05$). Elliott and Luker (1997) agreed with many participants of this study that every member of the family was affected by one member's illness. Some nurses suggested that the parents were using denial as a coping strategy when they tried not to show their fear.

According to Tripp-Reimer and Sorofman (1998), the reluctance to show fear or express emotions was common among the members of the Greek culture, especially the men.

During the interviews many of the parents discussed their more difficult moments while caring for their child. Some of these periods were in agreement with Meleski's (2002) five periods of transition which include: diagnosis, during a parent's absence, increased symptoms, developmental milestones, and changes in the course of the illness. Most parents reported that they knew something was wrong, but the actual diagnosis was even more shocking than they had expected. This sample claimed 100% that diagnosis was the most difficult time, while Clements *et al.* (1990) found that only 70% of their parents claimed diagnosis as one of the most difficult periods.

Another difficult period was during a parent's absence when family reorganisation was needed to replace the missing family member. For example, the divorced parents reported how difficult it was for their children since the remaining parent needed to undertake more roles and responsibilities. Another woman mentioned that it was a problem when she needed to go to hospital to have a heart valve replacement. She had postponed her surgery for years because she worried how her deaf and mentally retarded child would adjust to her absence.

Other parents described how worried they were when their children needed hospitalisation and they were so relieved when their children returned home. Many pointed out that they valued routine and felt more secure when their children were at home with them. At times of increased symptoms, parents reported more problems in administering medication, and in planning and in carrying out treatments. Some parents seemed to ignore this stress and stated they were too worried about the condition of their child. How stressful these procedures were seemed to depend on the attitudes and self-confidence of the parents which was in agreement with Canan (1993) and Clubb (1998). Farley (1990) found similar responses in his study of the emotional responses of parents of disabled, premature, and chronically ill children. The parents reported feeling helplessness, frustration, depression, anger and irritability during periods when their

children experienced illness, needed to have surgery, started day-care, or were surpassed developmentally by a younger child.

Most of the parents interviewed appeared very sad when they talked about their child's missing developmental milestones, they expressed greater sadness when they described a younger sibling developmentally passing their child with a chronic condition. This was a period described by Clements *et al.* (1990) and Meleski (2002). Several mothers, and a father of an autistic teenager, described feelings of chronic sorrow during critical periods such as when their child did not speak or walk at the normal age and when their child was unable to enter school. This divorced father told how difficult it was when his child entered puberty. These parents agreed with the transition periods as described by Clubb (1991) for parents of children with autism and Down syndrome. When these particular milestones were not met, the parents were reminded that their child was not normal.

Regardless of the child's diagnosis, the parents reported becoming more upset during periods of transitions. However, the literature stated that parents coped better with these periods if they understood that it was normal to feel chronic sorrow and to use denial as a defence mechanism. Unfortunately, from the quantitative and the qualitative findings it was evident that not all nurses recognised chronic sorrow or what influenced the levels of stress that the families felt. Many nurses did not realise that the parents' emotional reactions were normal and that they often served the purpose of protecting them. The most common emotional reactions that parents express are denial and chronic sorrow, in accordance with Hentinen and Kyngas (1998).

Most parents expressed their pleasure with the educational training that nurses offered them concerning nursing skills they needed, which they felt was one of nurse's primary goals, this was also identified by Johnson (2000). The majority of the nurses were confident in their teaching skills to educate the parents by offering them the knowledge and skills they needed to adjust to their situation. However, many parents reported that they were not so successful in offering help in obtaining additional support or in modifying the parents' expectations of their child's abilities.

Many parents had trouble coping with these situations especially those who were uncomfortable with their child's care in general. Clubb (1991) reported that parents should be supported by nurses, yet many parents in this study were not supported resulting in their not being able to cope as well. Most of the nurses in this study did not help shorten the duration and lessen the degree of disruption that these difficult periods brought to these parents, which they could have done as suggested by Meleski (2002).

Most of the interviewed parents reported that they were afraid of what would happen to their child if they died before their child. The nurses appeared to understand that most parents fear greatly that they will die before their child and, thus, worry what will happen to their child. Many parents discussed the hope that their other children would undertake the care of the ill child. Since many children are young, it would be impossible to predict if this will happen or not. The parents' major fear was that the day might come when they would be forced to put their child in an institution.

The mass media has presented two different cases where the fathers have murdered their sons when the sons became a danger to society and to themselves. Of course the fathers went to prison, but they did what they felt they had to do since they had promised their sons that they would never send them to an institution. According to Midgeley's (1997) documentary of Greek institutions, the children there were not provided adequate care, education or emotional support. She visited Greek institutions and found children tied by their arms and legs to cots in rooms, which contained up to 30 cots. The two were state-funded institutions, the one in Karditsa housed 200 children while the other institute, in Serres, housed 100 children. However, the public health centre said that they had a policy of not rejecting any child and thus suffered from lack of space and shortages of staff. Even though this article was discussed earlier in the literature review, it was mentioned here to point out why Greek families have such a fear of institutions.

In this study, an additional fear that was presented by several parents was the "*fear of surgery*". They explained they did not fear the procedure itself, but the thought of the trauma that their child would experience when being taken to the operating room, and

again upon awakening in an unusual environment with strangers. These children with cognitive disorders would not be able to comprehend what was happening and no amount of reassurance could comfort them, according to their parents. One mother suggested a possible nursing intervention of having a specialized nurse visit these children pre-operatively, greet them in the operating room and stay with the child during the induction of the anaesthetic. Then the nurse would be free during the surgery but should join the child in the recovery room. In this way the child would not react so combatively or become so frightened.

It is suggested that most of the nurses were unaware that these parents had such a variety of fears according to their interviews, most nurses understood the fear of what would happen if the parent died before the child.

6.3. King's Interpersonal System

6.3.1. Nurses' Role of Offering Counselling and Psychological Support

A majority of nurses (68.7%) admitted that they felt uncomfortable in discussing children's diagnoses, which agreed with the impressions of the parents. A similar percentage of the parents (69%) reported that nurses felt uncomfortable when talking to them about their child's diagnosis. This was a non-statistically significant difference between the parents' and the nurses' perceptions ($\chi^2=0.03$, $p>0.05$). Most nurses (95.2%) understood the need for the parents to receive psychological support and most parents agreed (89.3%). In the chi-square test this resulted in a non-statistically significant difference ($\chi^2=1.41$, $p>0.05$). It must be pointed out that offering support was not the same as discussing the diagnosis with the parents. To discuss the various diagnoses the nurses needed to be kept up-to-date on a variety of illnesses and disabilities. Perhaps, as some nurses mentioned, they felt they did not have adequate information to provide to the parents, which was what made them feel uncomfortable.

Many nurses felt that the families should learn the diagnosis as soon as possible, while others felt they should have a period in which to adjust before being told their child's

diagnosis. It was often demonstrated during the interviews that most nurses and parents expected the diagnosis to be discussed only by the physicians. However, offering psychological support through the use of counselling techniques was considered a nursing skill by some nurses. In this study many nurses admitted that they did not feel confident with their listening and attending skills, making them feel inadequate and unable to approach the family and to offer support. Although it appeared that many nurses (96.4%) understood the emotions felt by the parents and were often being sympathetic, some nurses did not seem to understand that it was important for them to empathise and build a rapport with the family. This showed a statistically significant difference in the parents' and the nurses' perceptions ($\chi^2=52.35$, $p<0.001$). However, other parents (45.6%) expressed satisfaction with the nurses since they had showed empathy, communicated with them, provided them with information and appeared to have professional knowledge and skills.

Some nurses in this study reported that they were unprepared to offer counselling to parents. Burt (1995) discussed the lack of preparation concerning the role of nurses as counsellors. She suggested that adolescents, who were already sensitive about their "self" and sexuality, needed nurses to include them in discussions of sexuality. However, Burt (1995) argued that nurses usually felt uncomfortable talking about sexual subjects, which was seen in this study, since their educators had not prepared them for such topics. All nurses were not needed as sex therapists, but she suggested that they needed to be aware of the perceptions of body image and sexuality in order to help prevent these children from developing feelings of low self-esteem.

The benefits of psychological support as a therapeutic action may not be recognised by parents since many did not expect offering support or information as a nurse's role. Perhaps this was a cultural difference since Lugton's (1997) study in the UK reported that patients expected and needed nurses' support for them and their family. In her study, the health visitors interviewed pointed out that the families they cared for complained that they had not been given enough information.

These children and their parents have on-going needs that could be met by allowing nurses to carry out their role through the use of counselling skills. After evaluating the findings, it appeared that the participants in this study felt that it depended on the diagnosis, the nurse's confidence in her counselling abilities and the parents' respect for the nursing profession, as to whether the nurses' support was offered and whether or not it was accepted. However, not supported by the literature were the findings that many parents were not responsive to the nurses when they tried to offer their support.

Many parents in this study expressed their feelings of confusion when professionals discussed their child's illness and asked their opinion about certain subjects. Some parents verbalized their feelings that nurses had a lack of knowledge or training in their profession. One parent explained that to be polite, her family often said yes to the nurses even when they had no intention of complying. Attitudes like this could indicate a need for better communication skills and that nursing is not such a highly respected profession in Greece as suggested by Mahu (1999).

However, it must be noted that other parents expressed great satisfaction with the information they had received. Since the study was generically done, incorporating a wide variety of diagnoses, the parents' responses may have depended upon many variables since each illness carried with it different problems. For example, parents of children with diabetes had received more information since during the interviews the nurses expressed more confidence in talking to parents about diabetes while they lacked self-confidence in discussing rarer diseases, because they were unfamiliar with them. Included in this group were the priest and his wife whose two daughters had a rare condition, these parents complained that they had not received much information or support. A survey performed by Thomas and Corney *et al.* (1993) stated that their UK study found 97% of the community nurses felt inadequately educated and 91% of the nurses felt they needed more education.

Other parents stated that they were left alone to deal with a condition they knew very little about, if anything, and were trying to offer their children the best possible care.

They complained that due to the lack of information they lost valuable time because years ago when their child was first diagnosed no information or rehabilitation was offered. By the time their child reached school age the important developmental years had been lost. This was in accordance with Groce and Zola (1993), they believed that many medical professionals do not understand the importance of early intervention and stimulation that is needed by disabled children.

Perhaps this may be the main reason why all the parents that were interviewed felt so helpless and expressed feelings of anxiety and distress when their children were first diagnosed. As seen in this study, nurses and especially community nurses could and should play an important role in helping parents and their children in adjusting to altered body image.

In response to role perception, it appears that there was a variety of perceptions among the parent and nurse sample concerning whether or not nurses had offered information, counselling or nursing rehabilitation. Many parents did not “*look up to*” the nurses and did not expect their professional opinion, however, some did express their satisfaction. It was unusual and disappointing to realise that so many nurses did not respect their role as an important and respected member of the health care team. This was in contrast to Groce and Zola (1993), who claimed that professionals whose words were respected by the members of society were physicians and nurses, this was not found to be as true in this study of Greek parents and nurses.

Some nurses suggested that their problem could be that they were not confident in their counselling skills, yet others suggested that parents did not show them much respect since the public was not aware of nursing education as being a part of higher education and that it is at university level.

In the findings it was found that nurses felt a lack of status, which can be compared to ascription as described by Parsons (1951). It might be suggested that through the education of the public, nurses could gain “achievement” and become more valued by the

public if they were informed that nurses have undertaken a four year university programme while many have postgraduate degrees.

These nurses indicated a need for a better-informed public concerning nursing education. It was explained by several nurses that people from the villages with lower educational levels, still think of nurses as “*nosokomas*”. That was the term used as “*nurse*” for the old-fashioned practical nurses that were chosen by a physician at age 12 to be trained to work in his clinic for minimum wage to care for his patients. These girls had not even finished high school, but it must be said that they offered nursing “*art*” in caring for their patients. Today the name has changed in Greek to “*nosileftria*”, which is translated as nurse. Educated nurses are no longer to be called “*nosokoma*” but the term “*nosileftria*”. Unfortunately, the name has not been accepted as most of the public, including the mass media, still use the term “*nosokoma*”. Nurses today need to pass very difficult university entrance examinations with very high scores in order to attend a four-year polytechnic or university programme. Thus, they are not “*nosokomas*” but very professionally educated nurses. Many of the nurses reported that the public was unaware of these changes and did not respect nursing as a profession, which might explain why parents were not expecting emotional support and information from nurses.

Although nursing education has improved, Mahu (1999) suggested that there were still many problems associated with the nursing profession. She reported on an article offering data about nursing in the Greek National Health System by Plati *et al.* (1998), as cited by Mahu (1999). Mahu believed the low number of 172 university-educated nurses must all be found in Athens since she could not find one in her visit throughout Greece. She believed that the prediction of the doubling of university nurses would not happen soon because there were too many obstacles, since nursing was not considered a “*profession*” and nurses were still viewed as “*handmaidens*”. Standards of care were not identified and nursing after-care was missing. She closed with a positive note that perhaps great changes would occur in the 21st Century since it was too late for the 20th Century.

However, Kalokerinou *et al.* (1998) wrote about Greek community nursing and that new legislation had been passed concerning primary and home-care services, which would improve community nursing services. They claimed that nurses in Greece lacked the special education to fulfil their role within the community, which could be a reason why many nurses in this study had not offered home visits or sufficient counselling and information, according to most parents. The findings of this study suggested that public awareness was needed concerning the improved educational levels of nurses today. The communities needed to become better informed concerning the scientific profession that nursing has become.

6.3.2. Stress-Chronic Sorrow

Regarding the stress and the possibility of these parents experiencing chronic sorrow and grieving for the loss of their perfect child, the descriptive analysis and the interviews gave evidence that the majority of nurses were unaware of chronic sorrow and its importance in helping parents prepare for the transition periods in which they suffer more. In turning to the literature, Hainsworth *et al.* (1994), Johnson and Marder (1994), and Lowes and Lyne (2000), reported support of these perceptions of grief relating to the loss of a part or function of a body part resulting in a change of body image. The depression that these parents felt was referred to by Olshansky (1962), as chronic sorrow. The subject was often discussed in the literature and most opinions were that it was important for nurses to be aware of chronic sorrow so they could offer emotional support to the parents (Meleski, 2002; Mallow and Bechtel, 1999; Bailey *et al.*, 1999; Johnson, 2000; Clements *et al.*, 1990). The periods of chronic sorrow would continue to exist, but with proper nursing interventions they could occur less frequently and last for shorter periods of time according to Hainsworth *et al.* (1994), Johnson and Marder (1994), and Lowes and Lyne (2000). Further studies are needed to explore the possibility of this being a key factor in improving the adjustment strategies for the Greek parents of chronically ill and disabled children.

A few fathers, in this study, mentioned that they felt that society expected them to be strong and, thus, they tried not to openly express their grief. These fathers complained

that family and friends worried more about how their wives were coping, which made them feel left out. They mentioned feelings of conflict, distress, disappointment and depression. The men explained that they preferred direct action, such as seeking help, while they felt that their wives preferred indirect action, such as crying when they needed help.

However, many parents expressed the opinion that grief can have a positive side since these parents claimed it involved love, humility, relief and acceptance. According to Meleski (2002) some families experienced minimal disruption and found improved closeness within the family relationship, which was in agreement with Kearney and Griffin (2001). Hatton *et al.* (1995) mentioned that a few fathers found positive aspects of having a child with CHP, such as heightened bonding with their child and a better father-child relationship. It appeared that some parents, although never accepting what had happened to their child, had managed to adjust and adapt to the changes within their family life. Other parents mentioned that siblings suffered since they lacked attention, or they had too many responsibilities placed on them to make up for the inabilities of their sibling.

A few mothers mentioned that their relationship with their husband had become strained due to lack of time spent together without their child, and their lack of adequate sleep. They discussed their feelings of guilt and other's accusations of blame. Some of these children had genetic diseases, such as Mediterranean Anaemia, Down syndrome and haemophilia, which increased these parents' guilt feelings. Their anger sometimes turned to blame which had divided some couples. The other parent was unable to cope with the child's diagnosis as explained by one father who had raised his son, an autistic child, alone for the last 16 years. Another woman stated that her husband was very devastated by the diagnosis of their child's condition and he suffered with phases of depression and anger. He attempted to escape the problem through the use of alcohol and later abandoned his family.

6.4. King's Social System

6.4.1. Community-Social Stigma

In attempting to explore the psychological aspects of care, social acceptance and stigma were included. There was a discrepancy between the nurses' and the parents' perceptions, as showed by descriptive analysis and the interviews, as to the acceptance of such children within their community. The chi square test showed a statistically significant difference in the parents' and the nurses' perspectives ($\chi^2=52.35$, $p<0.001$). Most parents (67%) felt their children were accepted by the community, while only 18% of the nurses felt these children were accepted. In the literature, Northway (1997) claimed that health care professionals often unwillingly contributed to the social isolation of disabled and handicapped people. However, it could be possible that the children of this study, most of them being born and raised in small communities were accepted within the small society of their communities.

Another area of disagreement between the two groups' perceptions, verified by descriptive analysis and the qualitative portion of the study, was whether these parents derived joy from their children. This showed a statistically significant difference in the parents' and the nurses' perspectives ($\chi^2=18.76$, $p<0.001$). Only 50.6% of the nurses felt that these parents felt joy from their children. Most parents (81.6%) claimed that they received a lot of joy and happiness from their child and that they did not feel that their child was a "tragedy", which was in agreement with Kearney and Griffin (2001) and Northway (1991). It appeared that health care professionals, including nurses, often felt that anything less than the perfect child was part of a tragic event with many disheartening and frustrating experiences.

6.4.2 Public schools- Special schools

Erving Goffman (1963) described "impression management" by which people play-act to impress others. This was described when parents deny that their child or family are different. Goffman defines stigma as when the individual does not meet the stereotyped

expectations of the society in which he lives, thus it would seem possible to eliminate stigma by changing the stereotyped expectations. This offers parents some hope that through public awareness campaigns and by their children entering the community life by attending regular schools the stereotype would change. In this way the stigma against their child and their family would be eliminated

Insisting on public versus special school indicates that parents refuse for their children to be stigmatised. Parents finding support from parent support groups shows what Goffman (1963) suggests that these groups are the “own” group which allows these parents to feel normal since they all have the same experience as discussed in the Literature Review. Most nurses in this study seemed unaware of the importance of these two factors.

Another issue of importance was that many parents and nurses pointed out that not enough attention was given to offer full integration of disabled and chronically ill people into society. Most nurses expressed the feeling that special schools offered a wonderful opportunity for these children, while on the contrary, most parents felt that they created a worse situation for their child. One mother pointed out that the nurses did not understand that for a deaf child from a village with no other deaf children, “signing” could not help her child. There would be no one for her child to communicate with.

The disagreement concerning the schooling of these children was verified by the descriptive analysis and the interviews. The chi square test showed a statistically significant difference between the parents’ and the nurses’ perceptions ($\chi^2=35.72$, $p<0.001$). The majority of the nurses (72.3%) believed that the families should send their children to special schools, only 27.2% of the parents agreed. Most parents (72.8%) disagreed since they felt special schools further isolated their children from the normal community. By attending regular school their children would be kept in contact with their neighbourhood friends throughout their years of schooling. If their children were not mentally impaired, but had only physical impairments, after a normal school education they have the opportunity to proceed to the university. Special schools do not offer this option and parents believed that if their children were put in classes with mentally

incapacitated children, the classes would not advance quickly enough for them. It appeared that nurses did not understand this, and through this misunderstanding the nurses contributed to the children's social isolation. However, public schools were not for all children since there were children who were mentally impaired. These children needed special schools, since they would be unable to cope in public schools.

6.4.3. Parent-Support Groups

As identified in the literature review, stigma can be dealt with in several ways. As mentioned before, there are two groups in which the stigmatised feel normal, according to Goffman (1963). These groups were called the "own" group and the "wise" group. This could account for the findings of this study that most parents were fully in favour of parent support groups, since within these groups they felt normal. The "wise" groups of health care professionals, however, did not appear to make them feel so comfortable. The other ways of treating this status was sometimes observed as described by Hehir (2002) and Charmaz (1991). This was apparent when so many parents spoke out against special schools.

In exploring the perceptions between the two samples, it was found in the descriptive analysis concerning parent-support groups that more parents (88.3%) approved of them than the nurses did (75.5%). The chi square test ($\chi^2=5.83$, $p<0.05$) demonstrated a statistically significant difference between the two group's perceptions. This was in agreement with the nursing literature. Almeida (1995), Burke *et al* (1999), Carson and Heiber (2001) and Garwick *et al* (1998) reported that parents gained their main support from other parents and parent-support groups. The parents in this study approved of parent-support groups, which was another form of counselling as described by Carson and Heiber (2001). Group work encouraged by Almeida (1995) as a positive intervention for families whose children had diabetes. These groups offered support and assisted the families in their adapting to their new lifestyle. Parents offered each other emotional support and they became a cohesive group, allowing them to express negative feelings.

This cathartic process had a positive effect on families' overall coping, according to the parents' reports.

Many parents felt that even loving family members had not offered the same support as another parent had who really understood their situation. Results of a study by Wineman (1990) pointed out that support groups, along with the perceived support of family and friends, resulted in better psychosocial adjustments. However, some parents in this study reported that family members had not always been supportive and had caused them a great deal of pain by making comments such as, "*it would have been better if Anna had died!*".

6.5. Conclusion

In conclusion, the qualitative portion uncovered topics that had not been extensively addressed in the literature or by the questionnaires. Additional and unexpected findings were that most nurses seemed unaware that parents wanted their children to attend public schools, and that many parents believed that their children's CHP could have been prevented. The importance of religion to these families was an unexpected finding, an issue that had not been addressed in the questionnaire, which was a limitation to this study. Another interesting development was that some parents of children with cognitive health problems expressed having the additional fear of their child needing to undergo surgery.

Although nurses sometimes understood their role, they had not undertaken it due to peer pressure. It was disappointing that the majority of both groups felt it was the physician's role to discuss the diagnosis and that nurses were not well enough informed. However, there were nurses that had understood and carried out their role of offering psychological support to some parents. However, other parents refused to accept information from the nurses, a few nurses suggested that this could be due to the public's unawareness of nurse's improved level of education. This identified an important topic for research to determine if there is a possible stigma towards nurses and the nursing profession.

To answer the first research question, the degree to which these parents' and nurses' perceptions differed were not determined, thus, this question was only partly answered. Among the important issues for which these parents required psychological support were social stigma, fears for the future, and which schools were important for these children to attend.

The last two research questions concerned whether or not the parents' and the nurses' felt that nurses had carried out their roles of offering information, emotional support, counselling and nursing rehabilitation. Although this study demonstrated that sometimes nurses felt they had carried out their role, parents were not so positive, from these results it was not possible to identify the degree to which this was done, thus, these questions were only partly answered.

Perhaps the findings of this study suggest that there were role incongruence which King (1981) claimed interferes with two persons transacting. These findings suggested that most of these groups had not set goals and had not obtained goal agreement which would have lead to better coping for these parents (King, 1981). These results suggest that there is an important role that nursing education could play in influencing the development of better nursing practice.

6.6. Summary

Within this chapter the findings from the qualitative and quantitative portions of the study that were presented in the previous chapters were discussed along with the relevant literature. In the next chapter, the conclusions of the study, along with recommendations and a summary of the findings will be presented.

Chapter VII. Conclusions, Recommendations and Summary

Introduction

In the previous chapter the findings of both the qualitative and quantitative portions of this study were combined and discussed along with the relevant literature. This chapter includes the conclusions of each portion of the study, followed by recommendations for nursing research, nursing practice and nursing education. In conclusion, a summary of the most important findings of the study is presented.

7.1. Conclusions of the Qualitative Portion of the Study

This eidetic phenomenological study conducted interviews for the purpose of understanding the vivid descriptions of the parents' and nurses' "lived experiences". Thus, the researcher was actually the tool, and attempted to "bracket" her feelings, and to carry out the great responsibility to the participants of properly telling their narratives in such a way as to obtain all the richness and context of their experiences.

The parents responded by describing some long-buried memories, such as how they felt when learning of their children's diagnoses. Many reported that they were surprised to find themselves speaking through tears. The researcher felt fortunate to share such intimate moments with these parents.

The nurses introduced the claim that they were often too uncomfortable to carry out their nursing roles since they were afraid of being ridiculed by their colleagues. They were hesitant to go into the physician's territory and also they felt parents trusted the physicians more. However, others admitted that they were actually prepared to counsel some parents, depending on the child's diagnosis. The nurses who had approached parents said they did so when the child had a common diagnosis, such as diabetes or asthma, since they felt confident with these conditions. A few nurses pointed out that to offer support and encouragement meant that the parents would ask questions that they were unprepared to answer, so they thought it was better for them not to approach the

parents. However, a few nurses took the initiative and consulted with the physicians and read up on the more current treatments and had offered parents information. Another reason mentioned for not offering support was because the nurses claimed they did not possess self-confidence in their communication, counselling and nursing rehabilitation skills. Both groups felt it was the physician's role to discuss the diagnosis and that nurses were not well enough informed. A few nurses suggested that the problem was the public's unawareness on the improved level of education of the nursing profession.

It appeared that most of the parent participants wanted sensitive, truthful information but with hope, although not necessarily from nurses. Most parents reported that they had been hurt by remarks made by family members, friends, other children and even nurses. The families loved their children but were depressed because those around them considered their beloved innocent child to be a "*tragedy*" and "*the worst thing that can happen to a family*". Many parents expressed the need for society to be re-educated that these "*imperfect*" children were not disabled but our society, in its quest for perfection, does not respect them. They became "*handicapped*" according to Amvrazi (2003) because the environmental conditions were not made to accommodate their particular needs. Many parents felt that the illness or disability existed with its sorrows, but educating the public could have eliminated this extra pain caused by society.

An additional and unexpected finding was that most nurses seemed unaware that parents wanted their children to attend public schools. Also, the importance of religion to these families, along with many parents admitting that their children's CHP could have been prevented were important findings. Nurses appeared to be more aware of social stigma since most of them felt that these children were not accepted by society, but most of the parents felt they were accepted. Parents of children with cognitive health problems expressed the additional fear of their child needing surgery. Some parents expressed their resentment towards nurses for not understanding their desire for their children to attend public schools. An important topic for research is to identify not only social stigma towards these children, but also the possible stigma towards nurses and the nursing profession.

It was hoped that in the future a properly organized health system would exist so that a rehabilitation nurse would meet these parents immediately upon their child's diagnosis and the proper information would be provided concerning their fears, anxieties and expectations. Currently, this was not done according to the majority of both groups of participants in this study.

7.2. Conclusions of the Quantitative Portion of the Study

The aim of this study was to explore the perceptions of Greek community and hospital nurses along with the perceptions of parents of children with CHP in relation to the nurse's role of offering psychological support.

An attempt was made to answer the first research question, which was:

1. What are parents' and nurses' perceptions of psychological aspects of care?

Although differences were found, the degree of these differences were not determined which resulted in this question being only partly answered.

The last two research questions, which were:

2. Do nurses perceive that they offered these parents information, emotional support, counselling and nursing rehabilitation?
3. Do parents perceive that information, emotional support, counselling and nursing rehabilitation were offered by the nurses?

Although this study demonstrated that sometimes parents and nurses felt that nurses carried out their role, it was not possible to identify the degree to which this was done, thus, these questions were only partly answered. Perhaps the findings of this study suggest that there were role conflicts which King (1981) claims interferes with the two persons transacting, thus, many of these parents and nurses had not set goals and had not obtained goal agreement which according to King (1981) would lead to better coping for

these parents. This suggests an important role that nursing education needs to undertake to improve nursing developments which could lead to better nursing practice.

This exploration identified some differences between the parents' and the nurses' perceptions based on the descriptive analysis and on the statistical analysis used to compare the two groups' perceptions which was carried out by the chi-square or Fisher's exact test. These differences identified by the chi-square or Fisher's exact test were concerning the parents as sole caregivers, whether these children cared for themselves, and if these children lacked self-esteem. Also, statistically significant differences were found concerning whether or not it was a nursing role to evaluate parents' and children's adjustments, to offer encouragement for these children's future and if nurses should offer up-to-date information.

Concerning support, other statistically significant differences were found, such as if nurses had offered parents support at all and if they had offered this support over a long period of time, or if they had offered another treatment regime when one had failed. Another unexpected finding was that many nurses did not understand that most parents felt joy from their children. Statistically significant differences were found between the two sample's perceptions concerning the nurse's role in planning for these children's future.

Statistically significant differences were found in regard to the acceptance of these children by society and as to which schools were important for these children to attend. Surprisingly, there was a statistically significant difference as to whether these conditions could have been prevented. Both samples were in agreement that nurses were not well enough informed to offer information and many felt that it should not be a nursing role. Both sample groups agreed that it was proper for parents to withhold information from family and friends. Only a few nurses encouraged parents to send their children to public school as was verified by both groups.

There was a discrepancy concerning the nurses' feelings that they had offered counselling and support while most parents disagreed. In this study it was suggested by the nurses that often the parents were refusing to participate in positive interactions with them.

In summary, there was a need to improve communication between nurses and parents. It might be considered that some barriers exist to quality health care, which may be caused by many nurses' inadequate preparation of communication skills and knowledge of nursing rehabilitation. However, the nurses who recognised their role of supporting and informing parents were often ignored by the parents who did not want nurses to undertake these roles. Both groups expressed their beliefs that physicians should discuss with and inform the parents since both groups felt nurses were not well enough informed as seen in the descriptive analysis and the chi square test.

7.3. Recommendations

7.3.1. Recommendations for future nursing research

Future research studies are important for exploring the social processes involved in nurses' offering psychological support, counselling skills, information and nursing rehabilitating to parents caring for their children with an altered body image.

Longitudinal studies exploring the parents' needs for psychological support and the pattern of parental grieving are essential to provide information needed for effective care and support for all parents and their children with CHP. Further studies are needed to investigate stigmatisation of Greek families. Research could study the possibility of the elimination of social stigma by the integration of these children into public school at an early age, as a way of desensitising the other children, and to improve social acceptance of these children and their families. Additional insight is needed to determine if there is a problem with the public's respect toward the nursing profession since so many parents did not want information from nurses. Future research should investigate if there is a form of stigma placed on the nurse's role within the Greek society. However, nurses also clearly identified the needs that these parents had for support and information but many nurses claimed that they had been taught to believe that it was not their duty to provide it.

Although it is not possible to generalise, it must be noted that based on the findings of these samples, offering information, counselling, support and nursing rehabilitation may not be considered by all nurses as nursing duties at this time, however, some nurses did recognise these as nursing roles.

7.3.2. Recommendations for nursing practice

Nursing education and continuing education programmes for nurses may be the key to offering successful holistic nursing care. Nurses could become empowered with knowledge which would provide confidence for them to undertake their role and to offer the best possible care. Counselling techniques, once learned, could easily become well developed and implemented in everyday nursing practice and offer invaluable support to parents of chronically ill children. If a nurse felt confident in her role as the supporter of these families, she could gain the respect of the parents along with that of the other health care professionals. Creating public awareness of the importance of nursing is very important.

Role incongruence was suggested concerning the parents' lack of understanding that an important part of nursing rehabilitation was the evaluation process in clinical practice. This evaluation is essential to provide the information for the nurses to develop an appropriate plan of rehabilitation. The majority of both samples agreed that within the community and hospital setting, nursing rehabilitation needed to place more emphasis on psychological rather than only physical problems. However, many nurses and parents were unaware that nursing rehabilitation was a special practice area for nurses.

According to most of the parents in this study, each child received different care based on their parents' search for help and that there was no consistency in care. Clinical nurses should be encouraged to take on their role of offering advice and information. Parents need nurses to offer them counselling skills, emotional support, information and nursing rehabilitation throughout the difficult years of struggling to care for their children and to prepare these children to become useful members of society.

Another issue was that some nurses reported that community health centres were understaffed and not being used to their full potential. This study was insufficient to determine if this was so, and if so, why this happened. Within the community it was suggested by several Head Nurses that the centres were not used by all of the families due to social stigma. This needs to be improved so that health authorities can identify these children and protect them by offering them resources and education to their families and their communities.

7.3.3. Recommendations for nursing education

Greek nursing education needs to increase its courses concerning counselling skills and nursing rehabilitation which are a very important part of nursing in today's world. Nurses need to become more aware that they have an important role to fulfil towards these children and their parents. By carrying out this role they have the opportunity to carefully observe these children during routine visits and vaccinations since these visits could provide the opportunity to identify health problems. In this way, the nurse could refer the family to other health care professionals.

Continuing education courses could be developed to update nurses on family adaptation interventions to help these parents by preparing them for the transition periods that all parents suffered. This could result with more parents being made aware of their options in caring for their children.

Nursing education is needed to support improvement in care and daily life of the disabled. Educational courses concerning disability awareness training should be developed by including the input of disabled people. These courses are needed for public awareness of the disabled and their rights to live the same lifestyle as a non-disabled person. Recently, the Greek Nursing Association has just gotten a bill passed by Parliament which demands continuing education programs to be implemented. In this way, nursing will have the funding and opportunity to retrain nurses in counselling and rehabilitation nursing that many more experienced nurses are missing at this time.

7.4. Summary

To conclude, the most important findings of this study are identified:

- 1) Most nurses felt these children lacked self-esteem, but many parents disagreed.
- 2) Most parents and nurses were unaware of the nurse's role in nursing rehabilitation. However, there were parents who described nurses who had carried out their role in nursing rehabilitation.
- 3) Many nurses were aware of their role to evaluate the adaptation of the child and his parents, but most parents did not agree with this. The reason some nurses did not agree was that they were unaware of this action as an important part of nursing rehabilitation.
- 4) Most nurses and parents did not feel nurses were well enough informed, however, others disagreed and felt nurses had informed them. The nurses reported that it depended on the child's diagnosis, if it was a common illness they felt more comfortable approaching the parents.
- 5) Most nurses claimed that they had offered information and counselling skills but it appeared that many parents refused to accept them, perhaps, questioning the authority of nurses in Greece. However, parents were very satisfied with the nurses who had offered them information and support.
- 6) Some parents' expressed an additional fear that was not often included in the current literature, the fear of their child needing to have surgery.
- 7) In this study, the nurses' perceptions of the importance of these children attending public school did not agree with the parents' perceptions. The nurses did not understand that parents felt that attending public school was an important step to eliminating social stigma and isolation for their children.
- 8) A large percent of the parents felt that their child's illness or disability could have been prevented. This indicates another reason that these parents needed nursing support since these parents may have reasons for feeling guilty which could be explored through a parent-nurse relationship. This might also suggest a need for improved health promotion programs and genetic counselling to prevent CHP from occurring in the future.

9) Religion and its' importance was not included in the questionnaire since it had not been mentioned in the literature, this was a limitation to the study.

Fortunately, this omission of the quantitative portion was included in the qualitative portion since these parents emphasised the importance of their Greek Orthodox religion as a source of strength in helping them cope.

10) These findings suggested the possibility that the authority of the nursing profession was not recognised within the Greek community, which resulted in many parents disregarding the support and information offered by the nurse's.

11) Many nurses were unaware that parents often reported deriving joy from their children and that their children were not the "tragedy" that other family members and nurses believed.

12) The majority of parents favoured parent-support groups. However, not as many of the nurses realised the importance of these groups as a source of support.

In conclusion, due to the variety of the two samples' responses it was impossible to determine to what degree they agreed on which resulted in only partially answering the research questions as mentioned before. However, this study produced data, which added insight into the role of the Greek nurse's in offering psychological support to parents of children with CHP.

Appendix I. Parents' and Nurses' Questionnaire

QUESTIONS	
1	It is more demanding for parents to care for a child with CHP or disabilities than caring for a healthy child.
2	It is usually depressing for parents caring for children with CHP or disabilities.
3	Parents of children with chronic health problems or disabilities are the sole participants in their children's care.
4	Parents face many problems in their attempt to learn to live with their child's health problem.
5	Rehabilitation programmes should be developed for children with chronic health problems or disabilities.
6	Parents support groups bring positive results in helping parents cope with their child's health problem.
7	I believe that children with chronic health problems or disabilities are accepted by society.
8	Children with CHP or disabilities are capable of caring for themselves.
9	I have often offered support and encouragement to parents of children with CHP
10	Nurses should suggest to parents other treatment regimes when one method fails.
11	Nurses need to encourage parents and their ill children to plan for a productive future.
12	Conditions that result in body image alteration can be prevented.
13	Nurses need to offer parents of children with chronic health problems or disabilities additional supportive care for a long period of time.
14	Children with chronic health problems or disabilities should go only to special schools and not public schools.
15	Nurses should not encourage parents to send their children to public schools.
16	Nurses should offer information even if it is discouraging.
17	Parents should have the right to withhold information about their child's illness from their family and friends.
18	A goal of nursing care is to provide hope and encouragement for parents and children with health problems.
19	It often helps parents feel better by talking to other parents about their child's health problems.
20	Parents often think about the nurses who have cared for their child.
21	I feel uncomfortable talking to parents about their child's diagnosis.
22	Physicians are the only qualified personnel to offer information to parents concerning their child's

	condition.
23	It is the nurse's role to evaluate how well the child and his family are adjusting.
24	Nurses should attempt to answer the parents' questions since they are well enough informed.
25	When dealing with the parents, nurses do not need to understand the grieving process since the parents have not lost their child to death.
26	Children with chronic health problems or disabilities often feel inadequate and lack self esteem.
27	Nurses should encourage parents to plan for their child's future and encourage independence at every opportunity.
28	Nurses need to provide families with up to date information concerning medical problems that their child could possibly face in the future.
29	I have made home visits and offered support to parents of children with chronic health problems or disabilities.
30	Parents often suffer from periods of sorrow and depression having felt they lost their "perfect" child.
31	Parents of children with chronic health problems often feel joy and happiness from their child.
32	Parents can gain happiness from the nurses' positive interaction with the child.
33	Nursing rehabilitation of children with chronic health problems or disabilities is very important
34	Nursing rehabilitation of children with chronic health problems or disabilities should be well developed and implemented in Greece.
35	Nursing rehabilitation of children with chronic health problems or disabilities should be based on personal needs that need to be addressed.
36	Nursing care and rehabilitation of children with chronic health problems or disabilities, should be focused more on the psychological rather than physical improvements.

**Appendix II. Description of the sample of 30 parents
that were interviewed**

Table 1: Parent's Gender

	Frequency	Percent
Male	10	33.3
Female	20	66.7
Total	30	100.0

Table 2: Parent's Age

	Frequency	Percent
<25 y	-	-
26-30 y	1	3.3
31-35 y	2	6.7
36-40 y	8	26.7
41-45 y	6	20.0
46-50 y	8	26.7
51-55 y	1	3.3
>56 y	4	13.3
Total	30	100.0

Table 3: Parent's Family Status

	Frequency	Percent
Single	-	-
Married	28	93.3
Divorced	2	6.7
Widow	-	-
Total	30	100.0

Table 4: Number of Children

	Frequency	Percent
0	-	-
1	3	10.0
2	19	63.3
3	3	10.0
4	3	10.0
5	2	6.7
Total	30	100.0

Table 5: Parent's Education

	Frequency	Percent
Primary school	11	36.7
High school	14	46.7
Polytechnics - University	4	13.3
Masters - Ph.D.	1	3.3
Total	30	100.0

Table 6: Parent's Occupation

	Frequency	Percent
Unemployed	2	6.7
Civil Servant	3	10.0
Teacher	1	3.3
Self-employed	4	13.3
Private Sector	3	10.0
Nurse	2	6.7
Housewife	12	40.0
Worker (Labourer)	1	3.3
Pensioner	2	6.7
Total	30	100

Table 7: Child's Diagnosis

	Frequency	Percent
Down's Syndrome	1	3.3
Haemophilia	1	3.3
Amputation	1	3.3
Physical disability (trauma)	1	3.3
Autism	3	10.0
Deafness	3	10.0
Mediterranean anaemia	1	3.3
Mental retardation	4	13.3
Cancer	4	13.4
Diabetes	3	10.0
Cerebral palsy	7	25.7
Renal failure	1	1.0
Total	30	100

**Appendix III. Description of the sample of 30 nurses
that were interviewed**

Table 1: Nurse's Gender

	Frequency	Percent
Male	2	6.7
Female	28	93.3
Total	30	100.0

Table 2: Family Status

	Frequency	Percent
Single	13	43.3
Married	14	46.7
Divorced	2	6.7
Widow	1	3.3
Total	30	100.0

Table 3: Number of Children

	Frequency	Percent
0	13	43.3
1	2	6.7
2	12	40.0
3	3	10.0
4	-	-
Total	30	100

Table 4: Education

	Frequency	Percent
3 years of studies	12	40.0
4 years of studies (TEI)	13	43.3
4 years of studies (AEI)	3	10.0
Postgraduate studies	2	6.7
Total	30	100.0

Table 5: Years of experience:

N	Min Value	Max Value	Mean Value	Std. Deviation
30	1	32	11.27	8.46

Table 6: Years in current position:

N	Min Value	Max Value	Mean Value	Std. Deviation
30	1	30	8.47	7.77

Appendix IV. Description of the parent sample who participated in the quantitative portion of the study (N=103)

Table 1: Gender

	Frequency	Percent
Male	34	33.0
Female	69	67.0
Total	103	100.0

Table 2: Age

	Frequency	Percent
<25 y	-	-
26-30 y	3	2.9
31-35 y	7	6.8
36-40 y	16	15.5
41-45 y	25	24.3
46-50 y	33	32.0
51-55 y	14	13.6
>56 y	5	4.9
Total	103	100.0

Table 3: Family Status

	Frequency	Percent
Single	-	-
Married	94	91.3
Divorced	7	6.8
Widow	2	1.9
Total	103	100.0

Table 4: Number of Children

No. Children	Frequency	Percent
1	7	6.8
2	70	68.0
3	16	15.5
4	8	7.8
5	2	1.9
Total	103	100.0

Table 5: Education

	Frequency	Percent
Primary school	21	20.4
High school	57	55.3
Polytechnics - University	24	23.3
Masters - Ph.D.	1	1.0
Total	103	100.0

Table 6: Occupation

	Frequency	Percent
Unemployed	5	4.9
Civil Servant	10	9.7
Teacher	7	6.8
Free Lancers	16	15.5
Private Sector	24	23.3
Social Worker	1	1.0
Nurse	3	2.9
Housewife	31	30.1
Labourer (Worker)	3	2.9
Pensioner	3	2.9
Total	103	100.0

Table 7: Child's Diagnosis

	Frequency	Percent
Haemophilia	4	3.9
Amputation	7	6.8
Physical disability	5	4.9
Asthma	3	2.9
Autism	7	6.8
Deafness	13	12.6
Down's Syndrome	6	5.9
Epilepsy	2	1.9
Head injury-disability	3	2.9
Mediterranean anaemia	3	2.9
Renal failure	2	1.9
Mental and physical disability	3	2.9
Mental retardation	14	13.6
Cancer	7	6.8
Diabetes	15	14.6
Cerebral palsy	9	8.7
Total	103	100.0

Appendix V. Description of nurses' sample who participated in the quantitative portion of the study (N=83)

Table 1: Gender

	Frequency	Percent
Male	6	7.2
Female	77	92.8
Total	83	100.0

Table 2: Age

	Frequency	Percent
<25 y	3	3.6
26-30 y	11	13.3
31-35 y	33	39.8
36-40 y	16	19.3
41-45 y	9	10.8
46-50 y	7	8.4
51-55 y	2	2.4
>56 y	2	2.4
Total	83	100.0

Table 3: Family Status

Family Status	Frequency	Percent
Single	26	31.3
Married	53	63.9
Divorced	3	3.6
Widow	1	1.2
Total	83	100.0

Table 4: Number of Children

No. of Children	Frequency	Percent
0	26	31.3
1	15	18.1
2	29	34.9
3	11	13.3
4	2	2.4
Total	83	100

Table 5: Education

Education	Frequency	Percent
3 years of studies (Hospital schools)	39	47.0
4 years of studies (Technological)	30	36.1
4 years of studies (University)	9	10.8
Postgraduate studies	5	6.0
Total	83	100.0

Table 6: Years of Experience

N	Min Value	Max value	Mean Value	Std. Deviation
83	1	32	11.76	6.74

Table 7: Years in Position

N	Minimum	Maximum	Mean	Std. Deviation
83	1	30	9.07	6.66

Appendix VI. Parents' Responses to the Questionnaire

PARENTS RESPONSES TO QUESTIONS (N=103)		Totally Disagree n / %	Partly Disagree n / %	Partly Agree n / %	Totally Agree n / %
1	It is more demanding to care for a child with CHP or disabilities than caring for a healthy child.	2 (1.9%)	-	17 (16.5%)	84 (81.6%)
2	I often feel depressed while caring for my child who has a CHP or disability.	5 (4.9%)	15 (14.6%)	40 (38.8%)	43 (41.7%)
3	Parents of children with CHP are the sole participants in their child's care	33 (32.0%)	23 (22.3%)	15 (14.6%)	32 (31.1%)
4	I have faced many problems in learning how to successfully care for my child's condition.	-	2 (1.9%)	49 (47.6%)	52 (50.5%)
5	Rehabilitation programmes should be developed for children with CHP or disabilities.	1 (1.0%)	1 (1.0%)	6 (5.8%)	95 (92.2%)
6	Parents support groups bring positive results in helping parents cope with their child's health problem.	10 (9.7%)	2 (1.9%)	16 (15.5%)	75 (72.8%)
7	I believe that my child is accepted by society.	8 (7.8%)	26 (25.2%)	40 (38.8%)	29 (28.2%)
8	My child can successfully care for her/himself.	22 (21.4%)	6 (5.8%)	36 (35.0%)	39 (37.9%)
9	Nursing staff members have often offered support and encouragement concerning my child's condition	35 (34.0%)	21 (20.4%)	34 (33.0%)	13 (12.6%)
10	Nurses have suggested other treatment regimes when one method has failed.	43 (41.7%)	16 (15.5%)	33 (32.0%)	11 (10.7%)
11	Nurses have encouraged me to plan for a productive future for my child.	57 (55.3%)	13 (12.6%)	17 (16.5%)	16 (15.5%)
12	My child's condition could have been prevented.	29 (28.2%)	25 (24.3%)	21 (20.4%)	28 (27.2%)
13	Nurses have offered support to me and my family over a long period of time.	41 (39.8%)	25 (24.3%)	27 (26.2%)	10 (9.7%)
14	Children with chronic health problems should go only to special schools and not public schools.	62 (60.2%)	13 (12.6%)	14 (13.6%)	14 (13.6%)
15	Nurses have not encouragement me to send my child to a public school.	-	-	5 (4.9%)	98 (95.1%)
16	Nurses should offer me information even if it is discouraging.	3 (2.9%)	1 (1.0%)	9 (8.7%)	90 (87.4%)
17	Parents should have the right to withhold information about their child's illness from their family and friends.	20 (19.4%)	6 (5.8%)	27 (26.2%)	50 (48.5%)

18	I expect encouragement and hope from nurses concerning my child's health problem.	6 (5.8%)	5 (4.9%)	34 (33.0%)	58 (56.3%)
19	It often helps me feel better by talking to other parents about our children's health problems.	3 (2.9%)	1 (1.0%)	41 (39.8%)	58 (56.3%)
20	I often think about the nurses who have cared for my child.	36 (35.0%)	19 (18.4%)	15 (14.6%)	33 (32.0%)
21	Nurses appear to feel uncomfortable when talking to me about my child's diagnosis.	9 (8.7%)	22 (21.4%)	37 (35.6%)	35 (34.0%)
22	Physicians are the only qualified persons to offer information to me concerning my child's condition	9 (8.7%)	6 (5.8%)	43 (41.7%)	45 (43.7%)
23	It is the nurses' role to evaluate how well my child and family are adjusting.	37 (35.9%)	43 (39.8%)	6 (7.8%)	17 (16.5%)
24	Nurses should attempt to answer our questions since they are well enough informed.	51 (49.5%)	29 (28.2%)	18 (17.5%)	5 (4.9%)
25	When dealing with the parents, nurses do not need to understand the grieving process since the parents have not lost their child to death.	15 (14.6%)	1 (1.0%)	45 (43.7%)	42 (40.8%)
26	Children with CHP often feel inadequate and lack self esteem.	24 (23.3%)	19 (18.4%)	40 (38.8%)	20 (18.4%)
27	Nurses should encourage parents to plan for their child's future and encourage independence at every opportunity.	12 (11.7%)	-	8 (7.8%)	83 (80.6%)
28	Nurses need to provide us with up to date information for possible future health problems.	48 (46.6%)	16 (15.5%)	31 (30.1%)	8 (7.8%)
29	Nurses visited my home and offered me support.	89 (86.4%)	6 (5.8%)	5 (4.9%)	3 (2.9%)
30	I often feel periods of sorrow and depression having felt the loss of my "perfect" child.	7 (6.8%)	3 (2.9%)	51 (49.5%)	42 (40.8%)
31	I often experience joy and happiness from their child.	6 (4.9%)	14 (13.6%)	30 (29.1%)	53 (52.4%)
32	I feel happy when I see the nurse interacts with my child.	6 (5.8%)	5 (4.9%)	37 (35.9%)	55 (53.4%)
33	Nursing rehabilitation is very important for my child.	1 (1.0%)	1 (1.0%)	16 (15.5%)	85 (82.5%)
34	Nursing rehabilitation should be well developed and implemented in Greece.	1 (1.0%)	19 (18.4%)	19 (18.4%)	64 (62.1%)
35	Nursing rehabilitation should be based on personal needs.	11 (10.7%)	18 (17.5%)	12 (11.7%)	62 (60.2%)
36	Nursing care and rehabilitation should be focused more on the psychological rather than physical improvements.	10 (9.7%)	9 (8.7%)	33 (32.0%)	51 (49.5%)

Appendix VII. Nurses' Responses to the Questionnaire

NURSES RESPONSES TO QUESTIONS N=83		Totally Disagree n / %	Partly Disagree n / %	Partly Agree n / %	Totally Agree n / %
1	It is more demanding for parents to care for a child with CHP or disabilities than caring for a healthy child.	4 (4.8%)	-	9 (10.8%)	70 (84.3%)
2	It is usually depressing for parents caring for children with CHP or disabilities.	2 (2.4%)	11 (13.3%)	49 (59.0%)	21 (25.3%)
3	Parents of children with chronic health problems or disabilities are the sole participates in their children's care.	-	1 (1.2%)	4 (4.8%)	78 (94.0%)
4	Parents face many problems in their attempt to learn to live with their child's health problem.	-	3 (3.6%)	43 (51.8%)	37 (44.6%)
5	Rehabilitation programmes should be developed for children with chronic health problems or disabilities.	-	-	6 (6.0%)	79 (94.0%)
6	Parents support groups bring positive results in helping parents cope with their child's health problem.	5 (6.0%)	17 (20.5%)	21 (25.3%)	40 (48.5%)
7	I believe that children with chronic health problems or disabilities are accepted by society.	10 (12.0%)	58 (69.9%)	14 (16.9%)	1 (1.2%)
8	Children with CHP or disabilities are capable of caring for themselves.	22 (26.5%)	27 (32.5%)	33 (39.8%)	1 (1.2%)
9	I have often offered support and encouragement to parents of children with CHP	-	3 (3.6%)	55 (66.3%)	25 (30.1%)
10	Nurses should suggest to parents other treatment regimes when one method fails.	-	-	11 (13.3%)	72 (86.7%)
11	Nurses need to encourage parents and their ill children to plan for a productive future.	1 (1.2%)	3 (3.6%)	35 (42.2%)	44 (53.0%)
12	Conditions that result in body image alteration can be prevented.	8 (9.6%)	23 (27.7%)	35 (42.2%)	17 (20.5%)
13	Nurses need to offer parents of children with chronic health problems or disabilities additional supportive care for a long period of time.	1 (1.2%)	-	30 (36.1%)	52 (62.7%)
14	Children with chronic health problems or disabilities should go only to special schools and not public schools.	7 (8.4%)	16 (19.3%)	20 (24.1%)	40 (48.2%)
15	Nurses should not encourage parents to send their children to public schools.	1 (1.2%)	-	19 (22.9%)	63 (75.9%)
16	Nurses should offer information even if it is discouraging.	1 (1.2%)	-	16 (19.3%)	66 (79.5%)
17	Parents should have the right to withhold information about their child's illness from their family and friends.	8 (9.6%)	11 (13.3%)	18 (21.7%)	46 (55.4%)
18	A goal of nursing care is to provide hope and encouragement for parents and children with health problems.	1 (1.2%)	3 (3.6%)	15 (18.1%)	64 (77.1%)
19	It often helps parents feel better by talking to other parents about their child's health problems.	9 (10.8%)	9 (10.8%)	27 (32.5%)	38 (45.8%)

20	Parents often think about the nurses who have cared for their child.	12 (14.5%)	13 (15.7%)	36 (43.4%)	22 (26.5%)
21	I feel uncomfortable talking to parents about their child's diagnosis.	6 (7.2%)	20 (24.1%)	42 (50.6%)	15 (18.1%)
22	Physicians are the only qualified personnel to offer information to parents concerning their child's condition.	9 (10.8%)	19 (22.9%)	24 (28.9%)	31 (37.3%)
23	It is the nurse's role to evaluate how well the child and his family are adjusting.	7 (8.4%)	12 (14.5%)	41 (49.4%)	23 (27.7%)
24	Nurses should attempt to answer the parents' questions since they are well enough informed.	11 (13.3%)	48 (57.8%)	16 (19.3%)	8 (9.6%)
25	When dealing with the parents, nurses do not need to understand the grieving process since the parents have not lost their child to death.	15 (18.1%)	13 (15.7%)	27 (32.5%)	28 (33.7%)
26	Children with chronic health problems or disabilities often feel inadequate and lack self esteem.	3 (3.6%)	15 (18.1%)	50 (60.2%)	15 (18.1%)
27	Nurses should encourage parents to plan for their child's future and encourage independence at every opportunity.	-	-	29 (34.9%)	54 (65.1%)
28	Nurses need to provide families with up to date information concerning medical problems that their child could possibly face in the future.	3 (3.6%)	-	23 (27.7%)	57 (68.7%)
29	I have made home visits and offered support to parents of children with chronic health problems or disabilities.	59 (71.1%)	21 (25.3%)	1 (1.2%)	2 (2.4%)
30	Parents often suffer from periods of sorrow and depression having felt they lost their "perfect" child.	2 (2.4%)	4 (4.8%)	28 (33.7%)	49 (59.0%)
31	Parents of children with chronic health problems often feel joy and happiness from their child.	29 (34.9%)	12 (14.5%)	18 (21.7%)	24 (28.9%)
32	Parents can gain happiness from the nurses' positive interaction with the child.	1 (1.2%)	-	19 (22.9%)	63 (75.9%)
33	Nursing rehabilitation of children with chronic health problems or disabilities is very important	10 (12.0%)	2 (2.4%)	9 (10.8%)	62 (74.7%)
34	Nursing rehabilitation of children with chronic health problems or disabilities should be well developed and implemented in Greece.	2 (2.4%)	14 (16.9%)	16 (19.3%)	51 (61.4%)
35	Nursing rehabilitation of children with chronic health problems or disabilities should be based on personal needs that need to be addressed.	11 (14.5%)	17 (20.5%)	12 (14.5%)	43 (50.6%)
36	Nursing care and rehabilitation of children with chronic health problems or disabilities, should be focused more on the psychological rather than physical improvements.	9 (10.8%)	2 (2.4%)	17 (20.5%)	55 (66.3%)

**Appendix VIII. Parents' and nurses' responses
(Items 1, 2, 4, 5, 13, 15, 16, 17, 18, 20, 29, 32, 33, 34)**

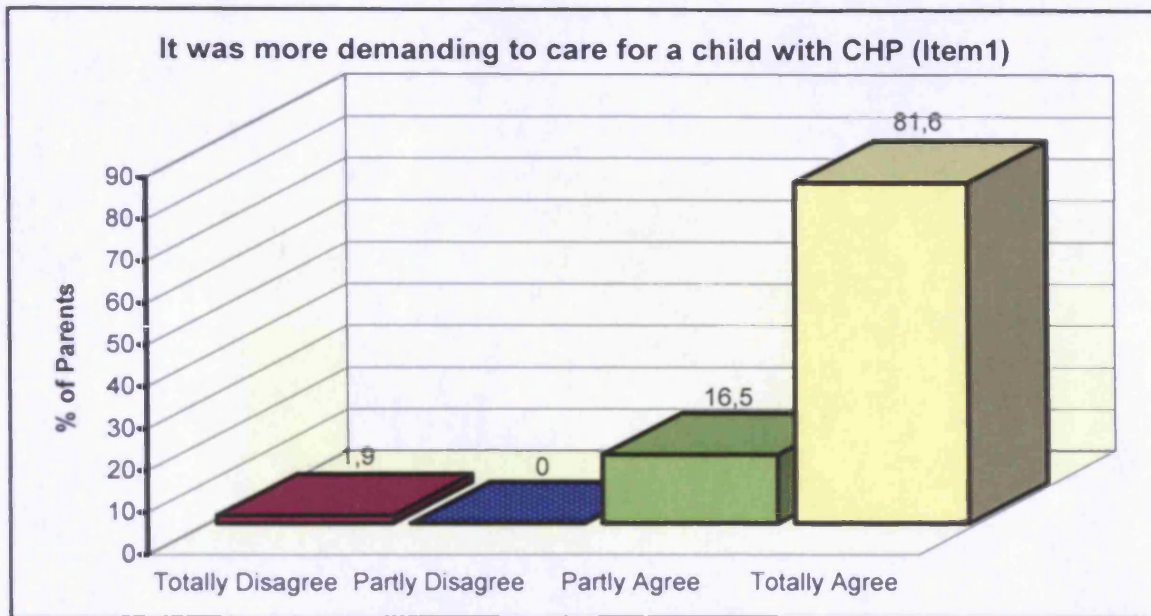


Figure 1. Parents' Responses - It was more demanding to care for a child with CHP (Item 1)

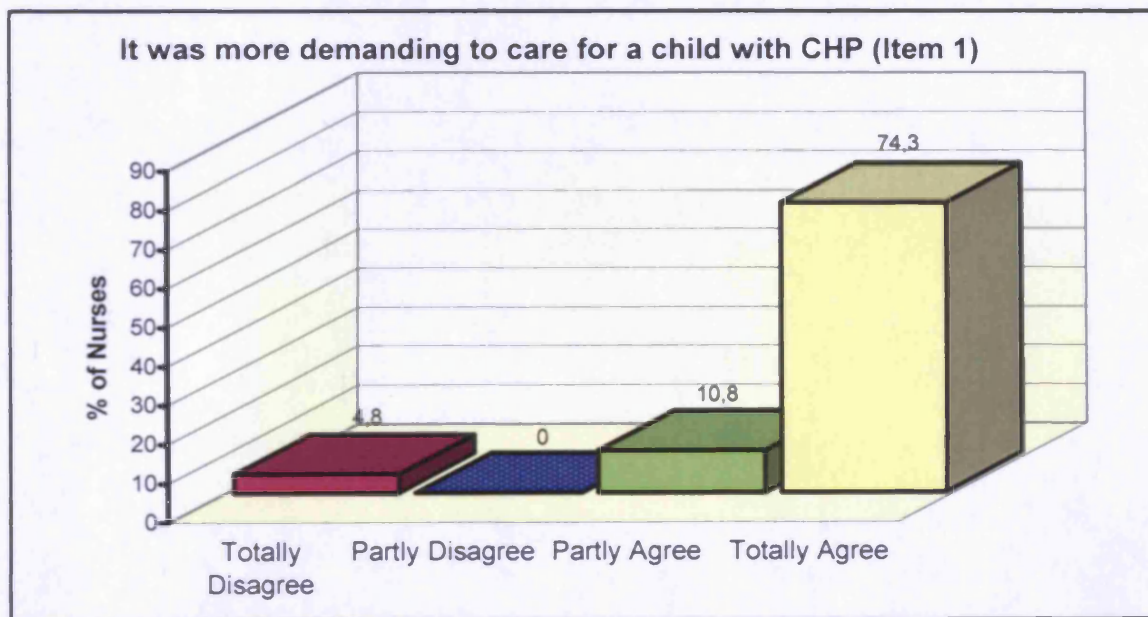


Figure 2. Nurses' Responses - It was more demanding to care for a child with CHP (Item 1)

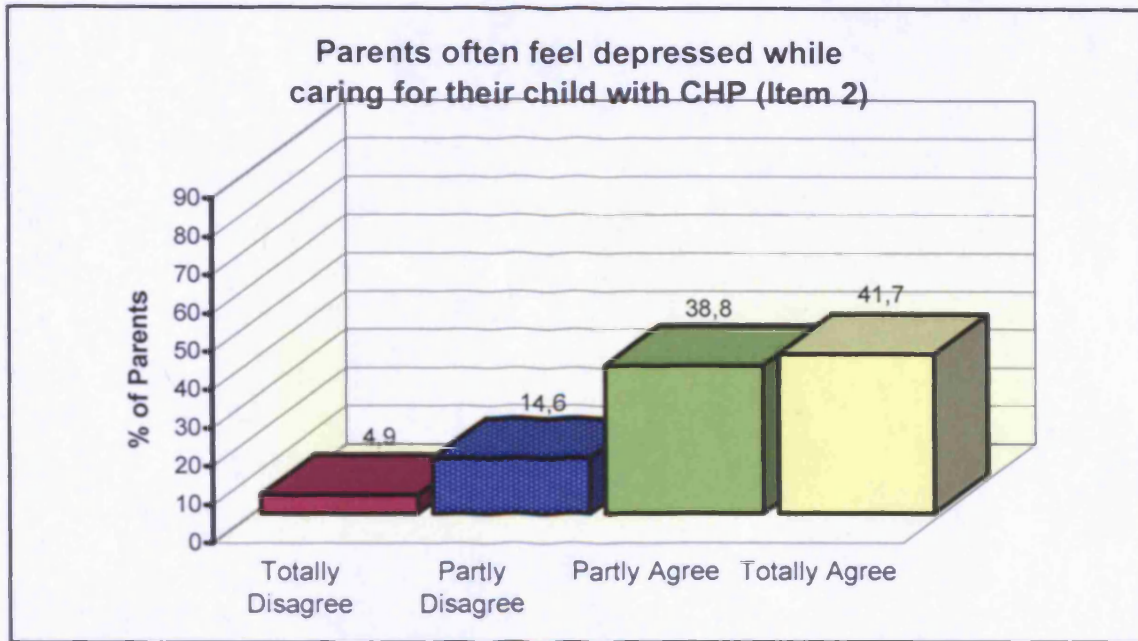


Figure 3. Parents' Responses – Parents often feel depression while caring for their child with CHP (Item 2)

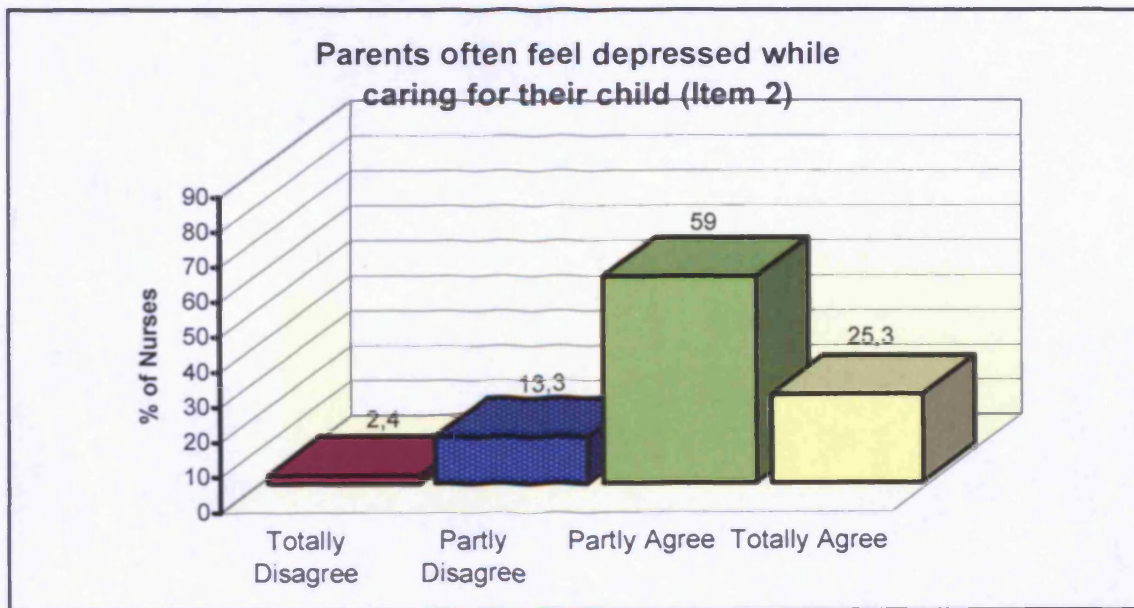


Figure 4. Nurses' Responses – Parents often feel depression while caring for their child with CHP (Item 2)

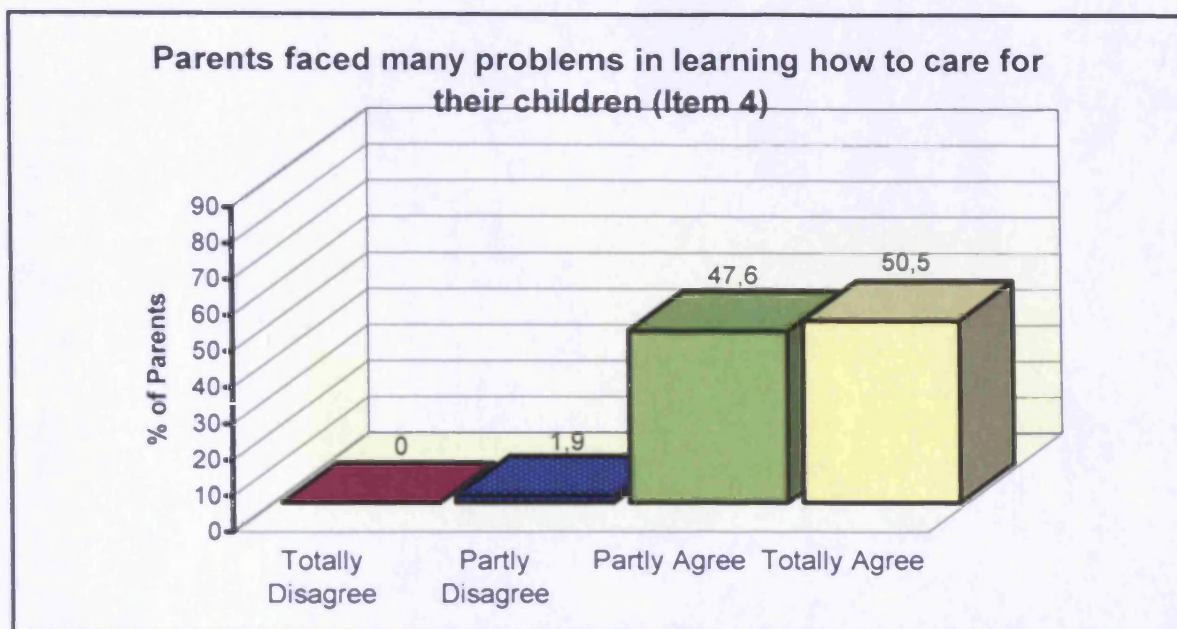


Figure 5. Parents' response - Parents faced many problems in learning how to care for their children (Item 4)

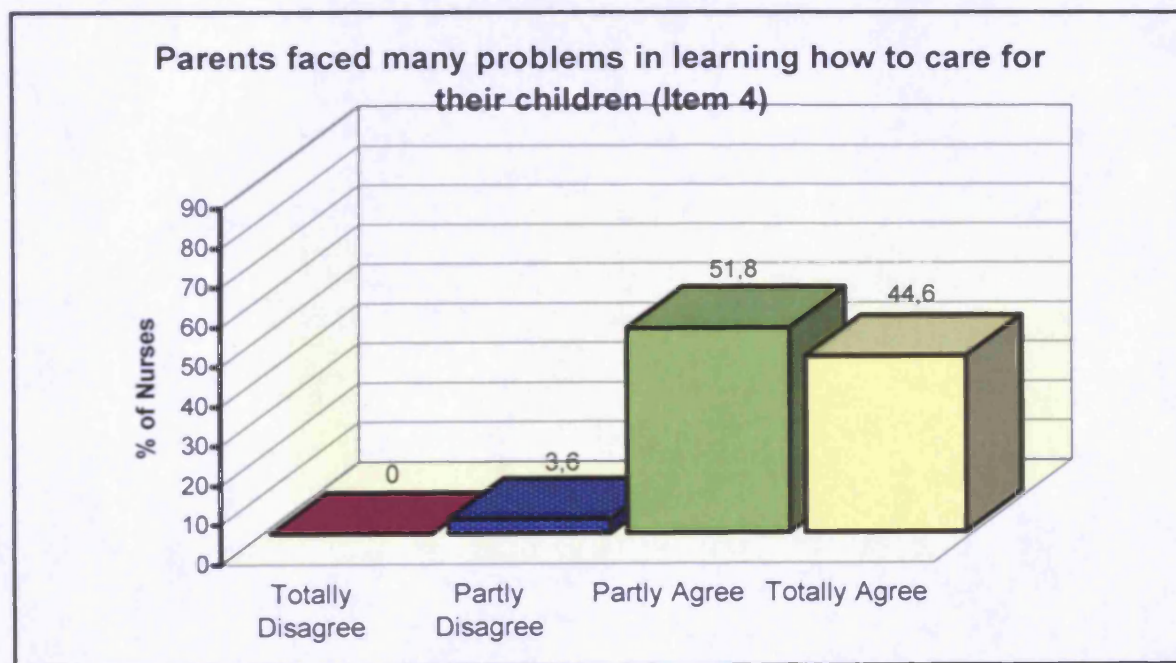


Figure 6. Nurses' response - Parents faced many problems in learning how to care for their children (Item 4)

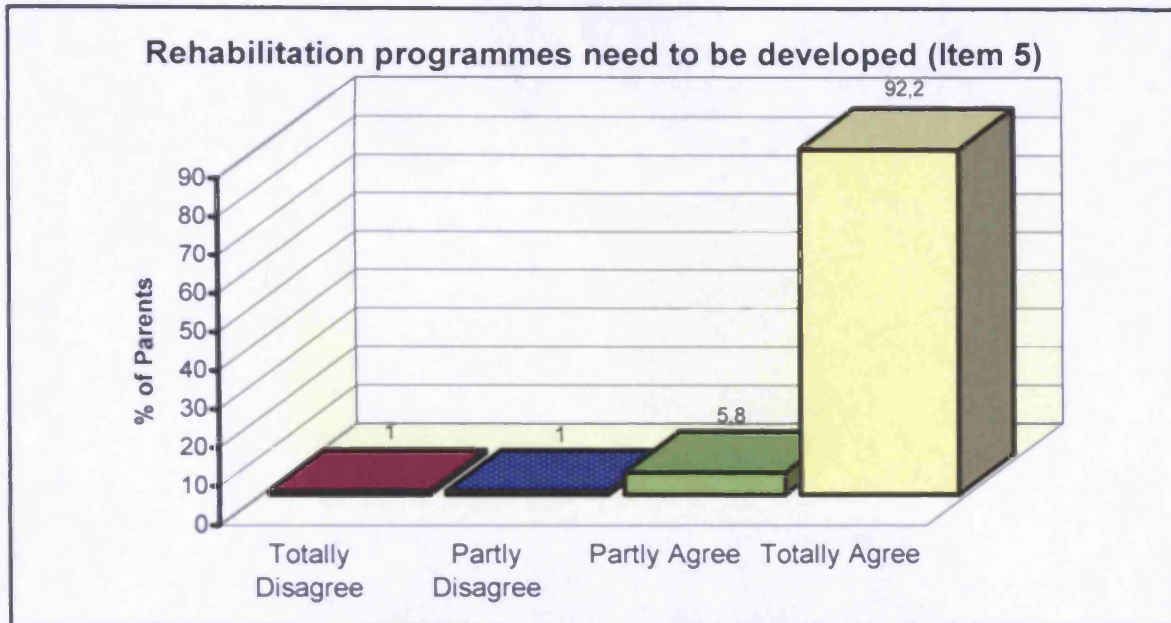


Figure 7. Parents' Response – Rehabilitation programs need to be developed (Item 5)

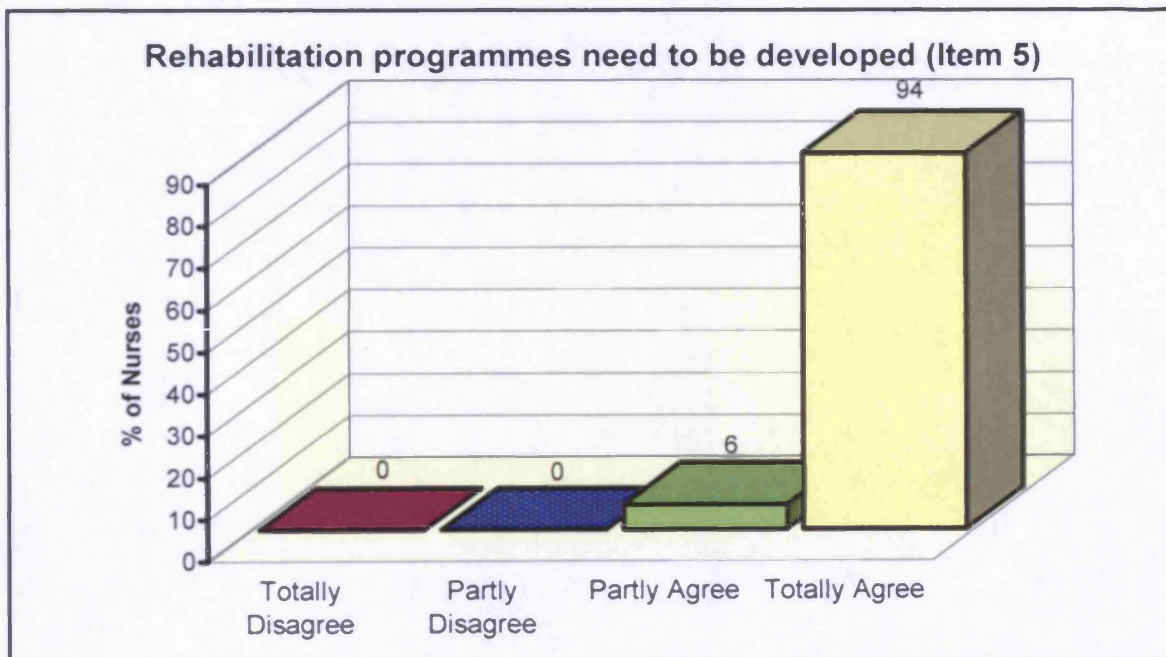


Figure 8. Nurses' Response – Rehabilitation programs need to be developed (Item 5)

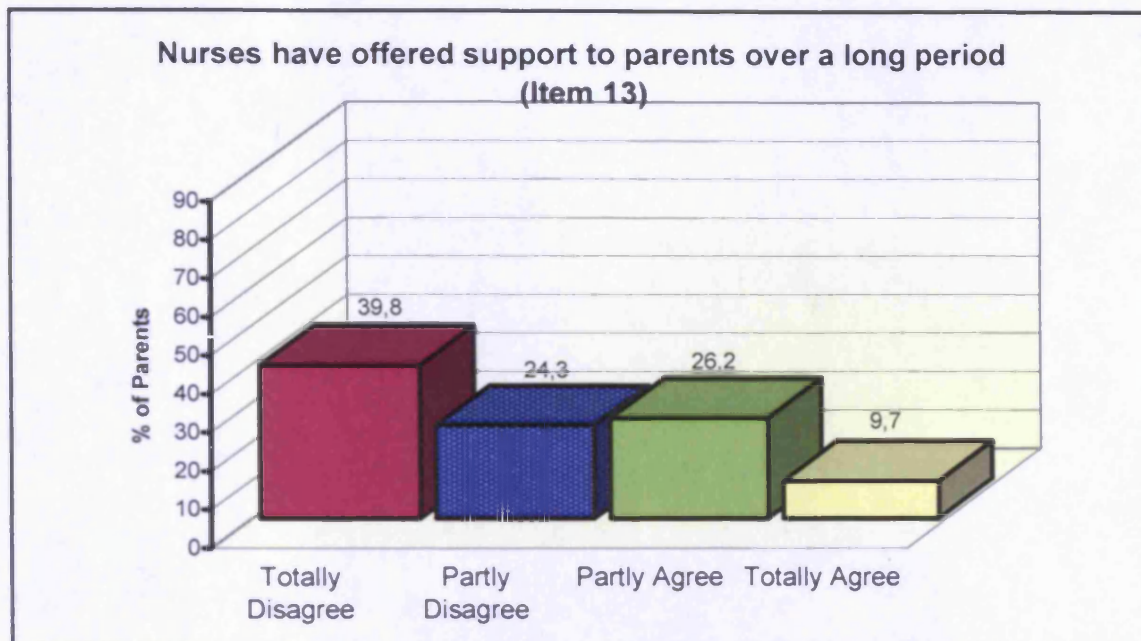


Figure 9. Parents' Responses – Nurses have offered support to parents over a long period (Item 13)

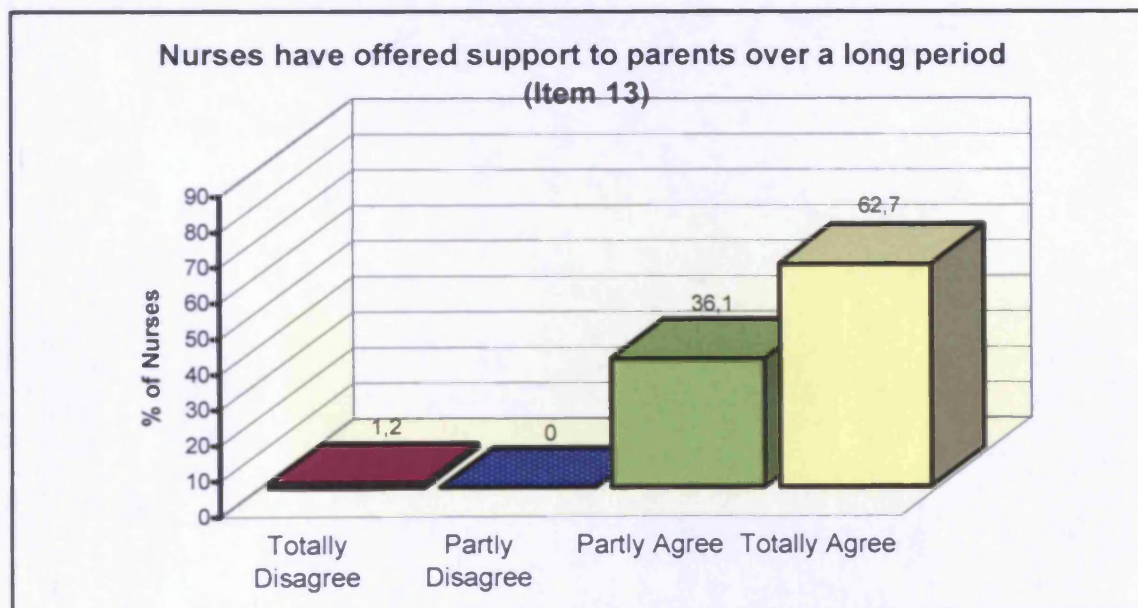


Figure 10. Nurses' Responses – Nurses have offered support to parents over a long period (Item 13)

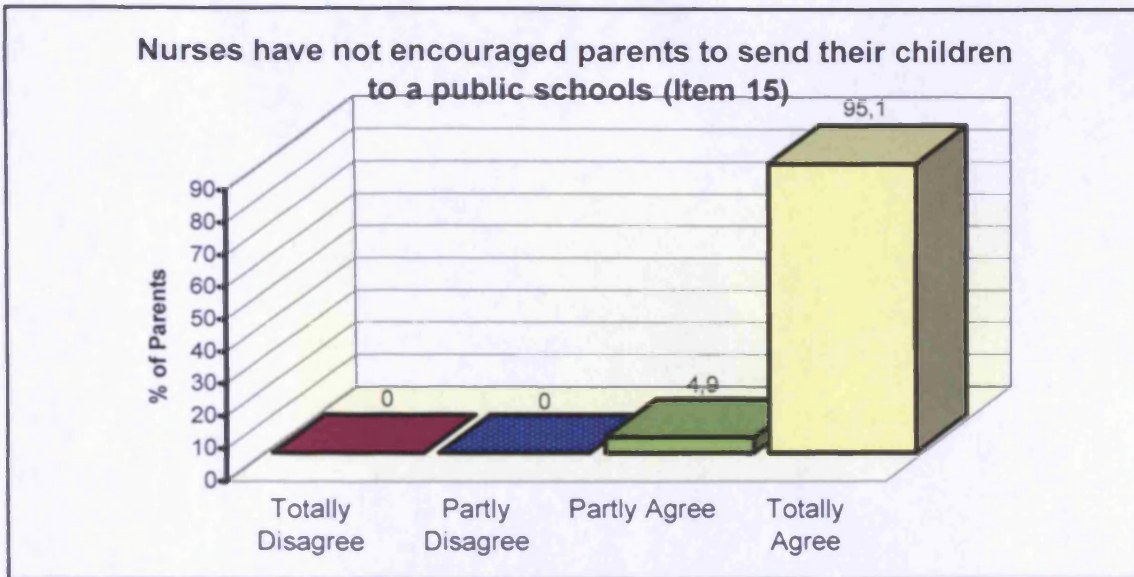


Figure 11. Parents' Responses – Nurses have not encouraged parents to send their children to a public school (Item 15)

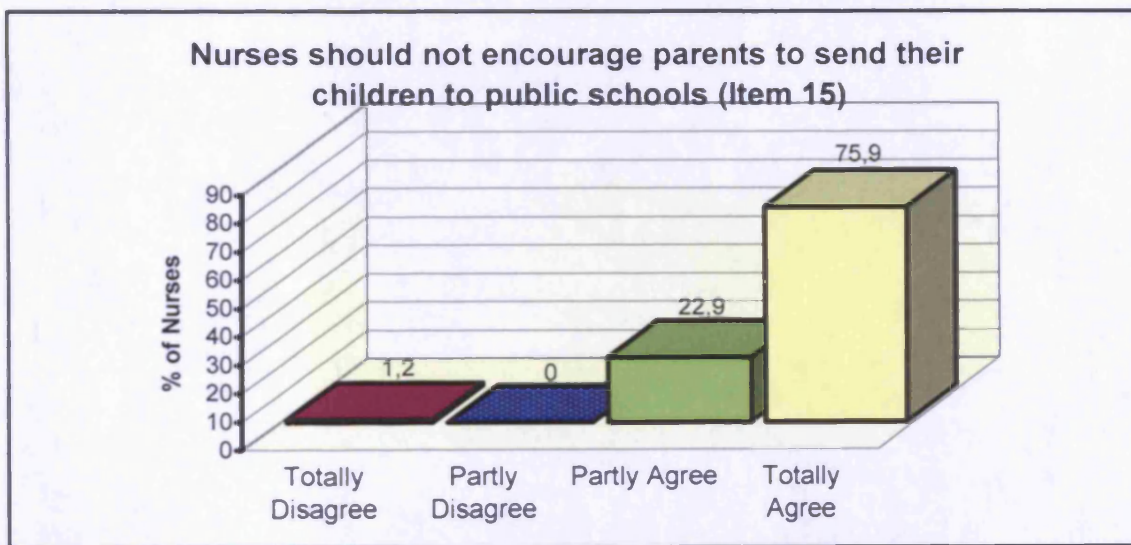


Figure 12. Nurses' Responses – Nurses should not encourage parents to send their children to a public school (Item 15)

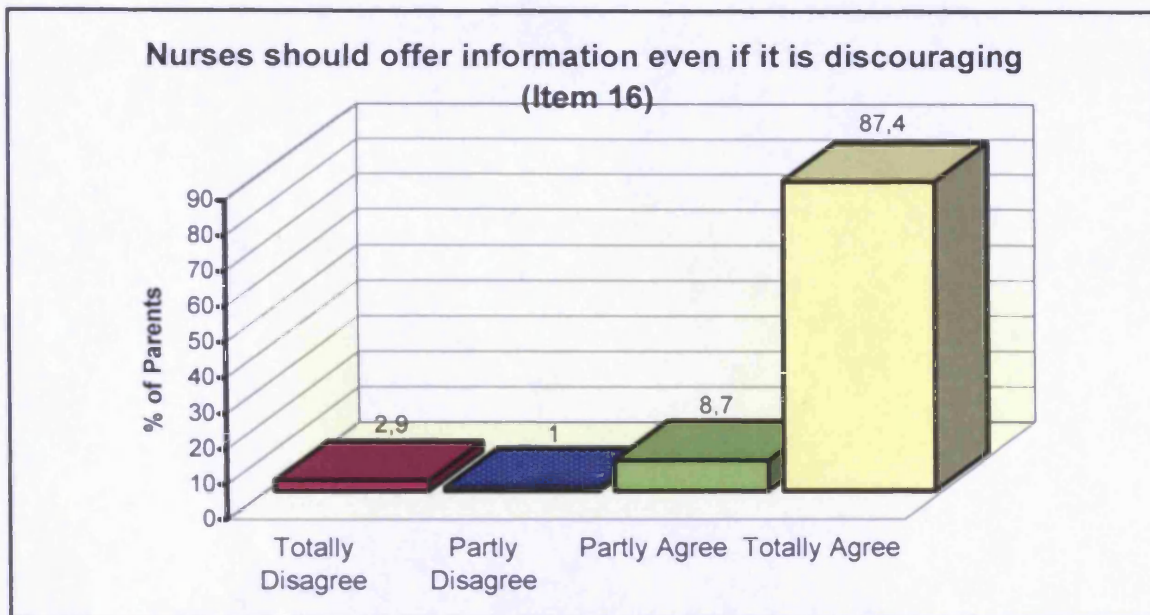


Figure 13. Parents' Responses – Nurses should offer information even if it is discouraging (Item 16)

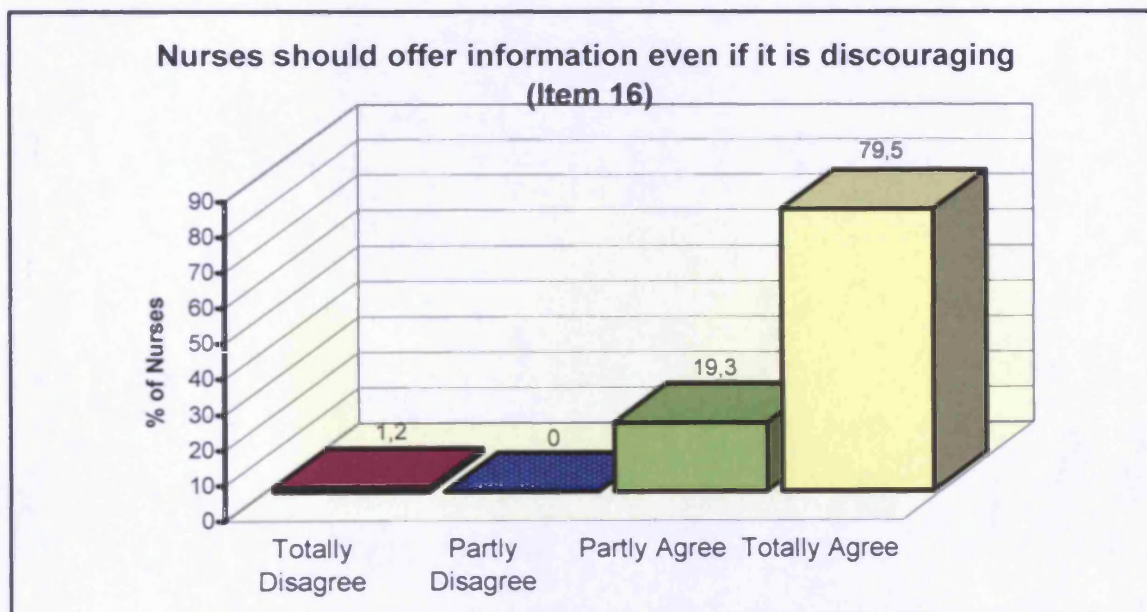


Figure 14. Nurses' Responses – Nurses should offer information even if it is discouraging (Item 16)

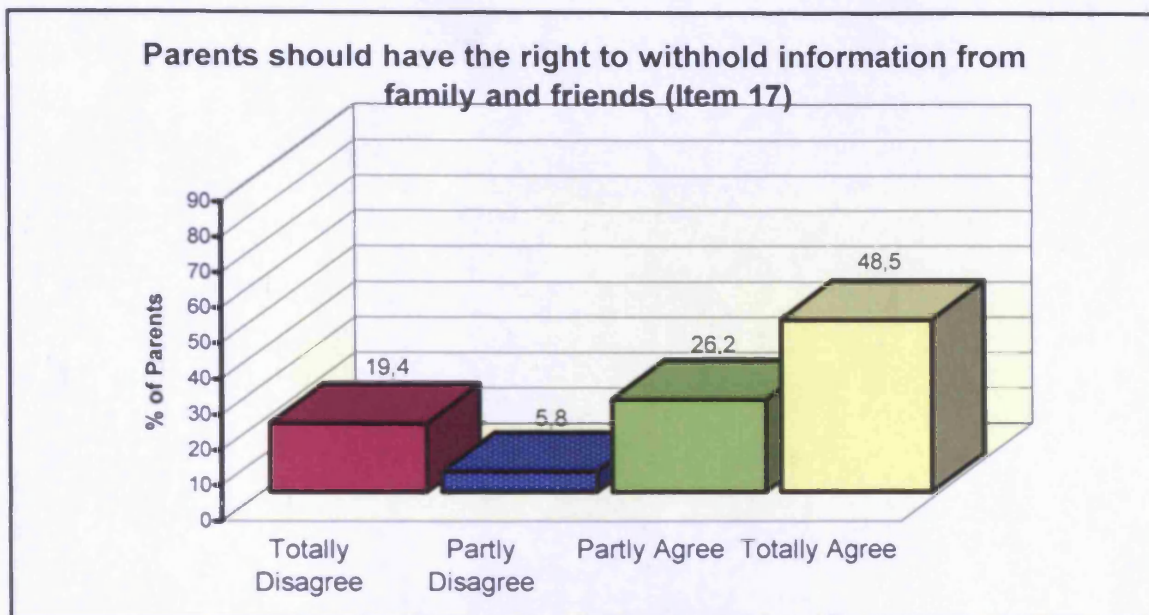


Figure 15. Parents' Responses – Parents should have the right to withhold information from family and friends (Item 17)

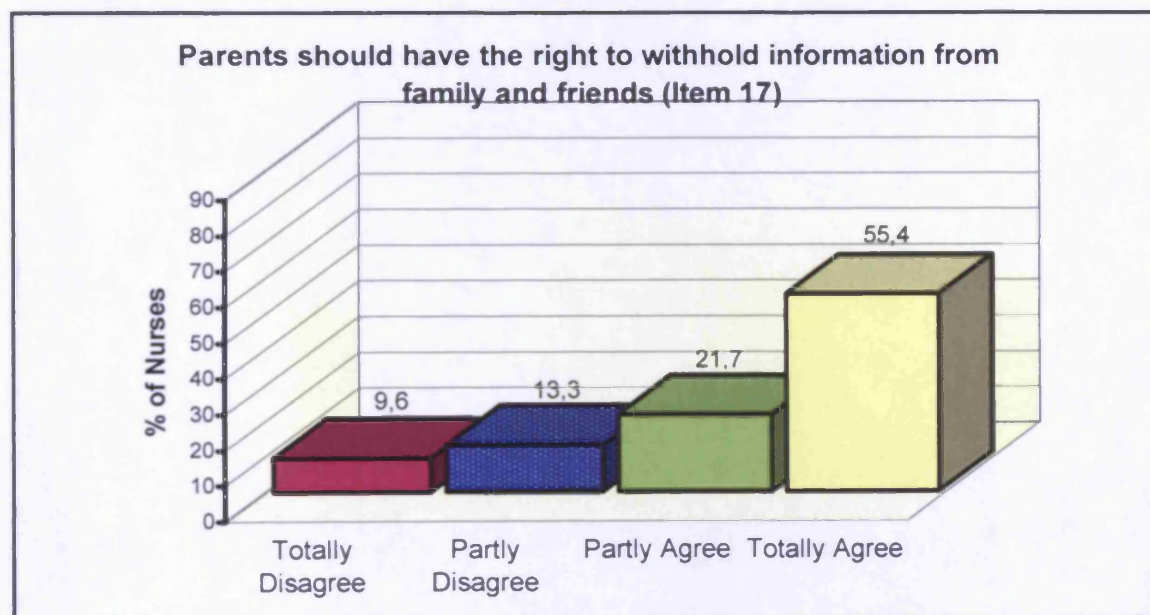


Figure 16. Nurses' Responses – Parents should have the right to withhold information from family and friends (Item 17)

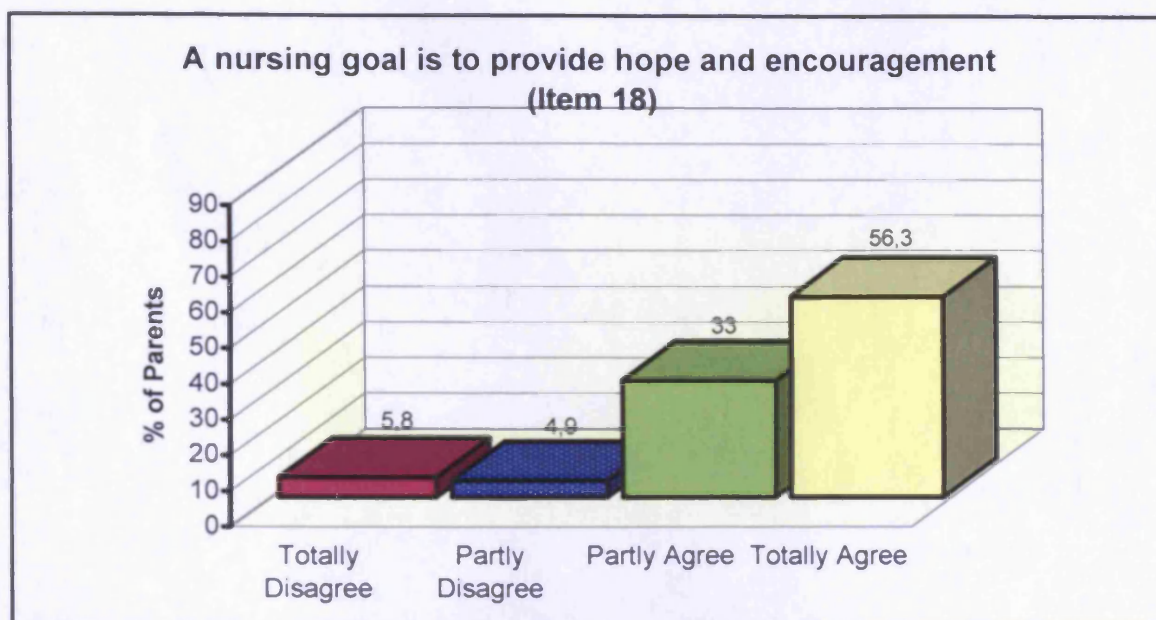


Figure 17. Parents' Responses – A nursing goal is to provide hope and encouragement (Item 18)

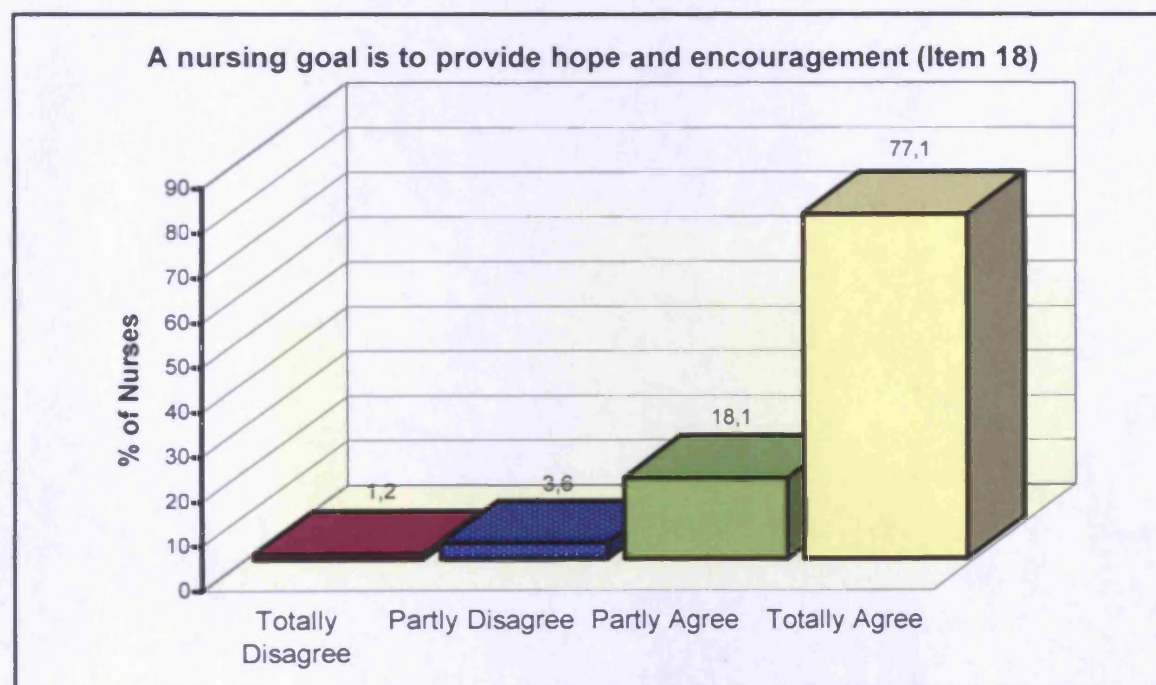


Figure 18. Nurses' Responses – A nursing goal is to provide hope and encouragement (Item 18)

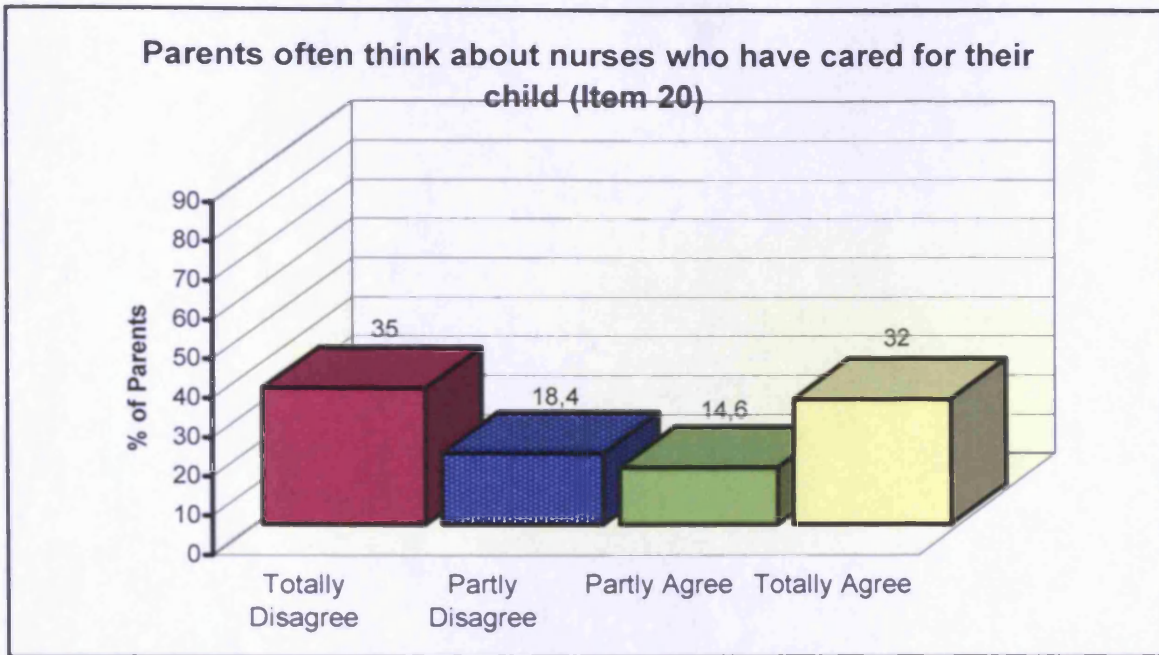


Figure 19. Parents' Responses – Parents often think about nurses who have cared for their child (Item 20)

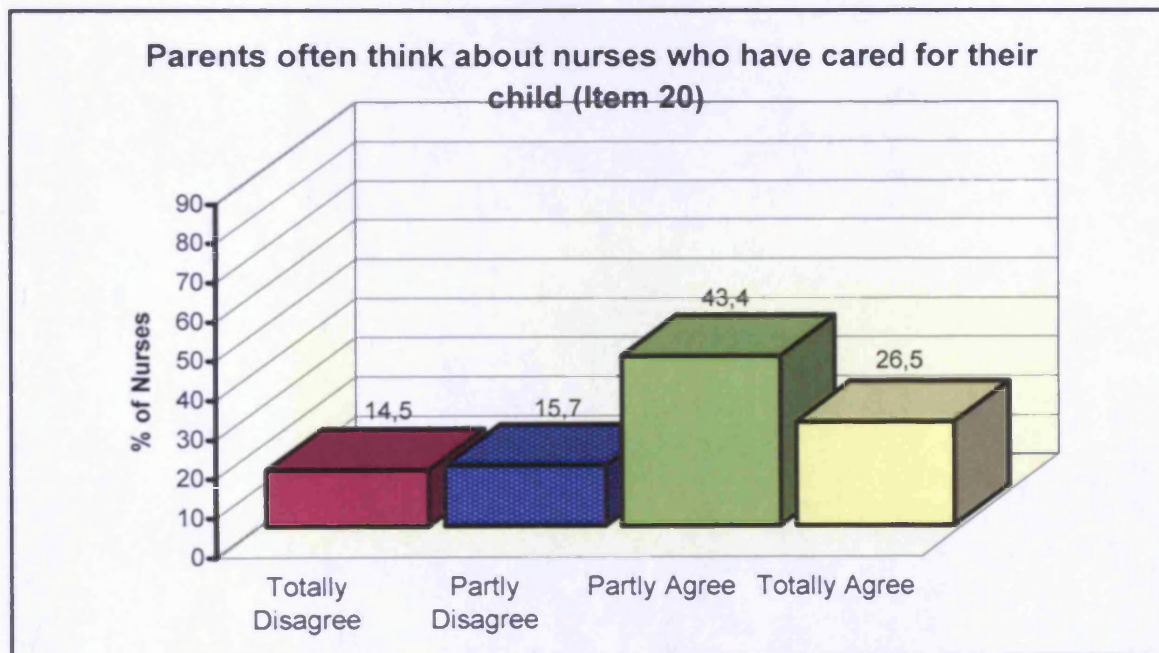


Figure 20. Nurses' Responses – Parents often think about nurses who have cared for their child (Item 20)

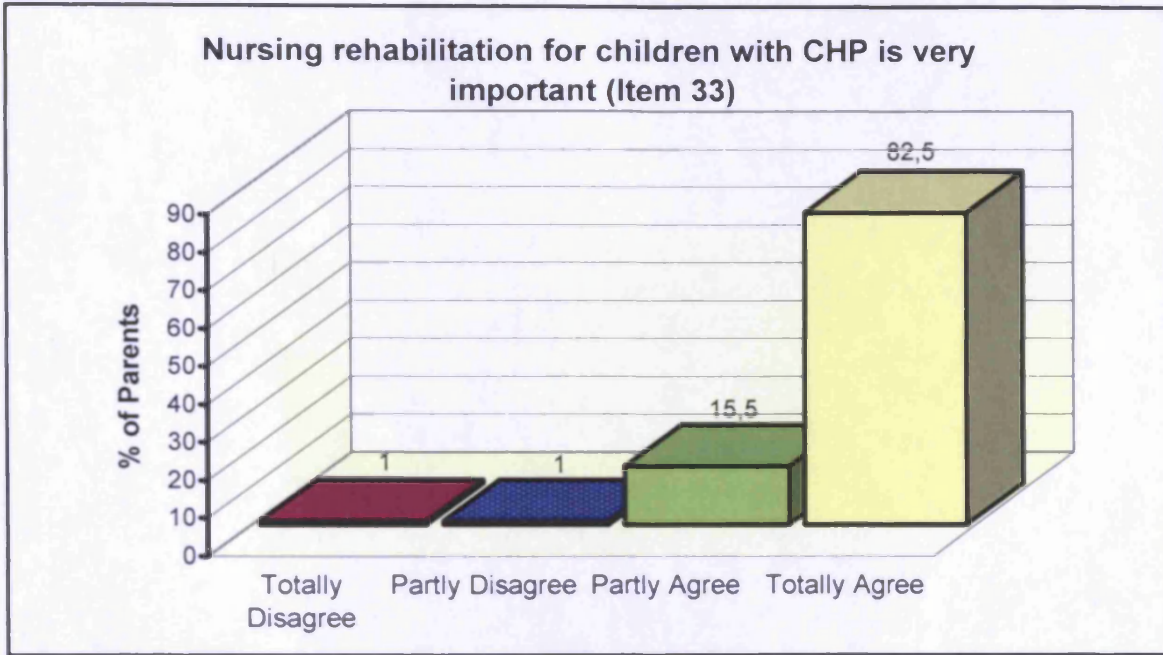


Figure 21. Parents' Responses – Nursing rehabilitation for children with CHP is very important (Item 33)

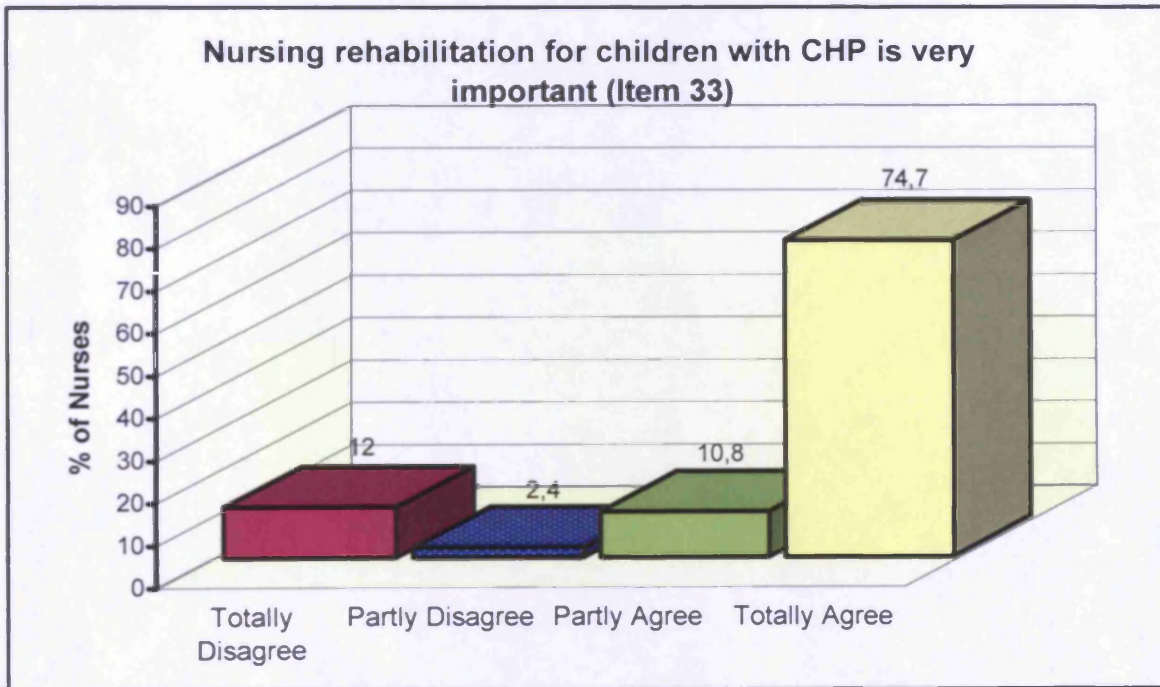


Figure 22. Nurses' Responses – Nursing rehabilitation for children with CHP is very important (Item 33)

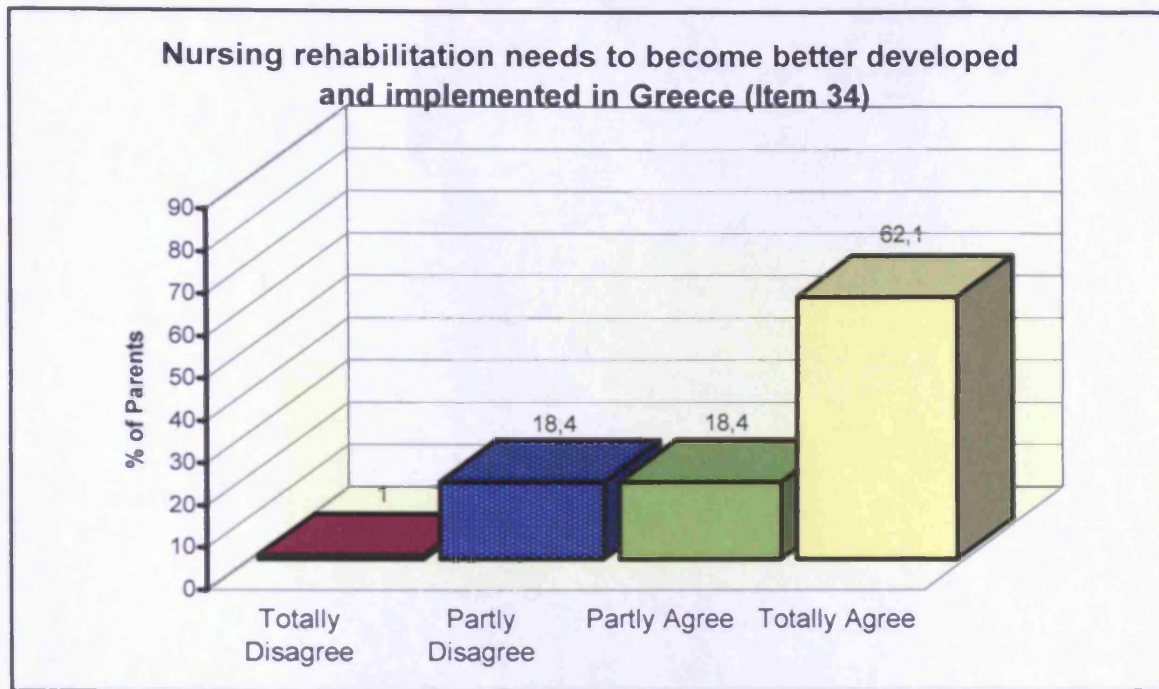


Figure 23. Parents' Responses – Nursing rehabilitation needs to become better developed in Greece (Item 34)

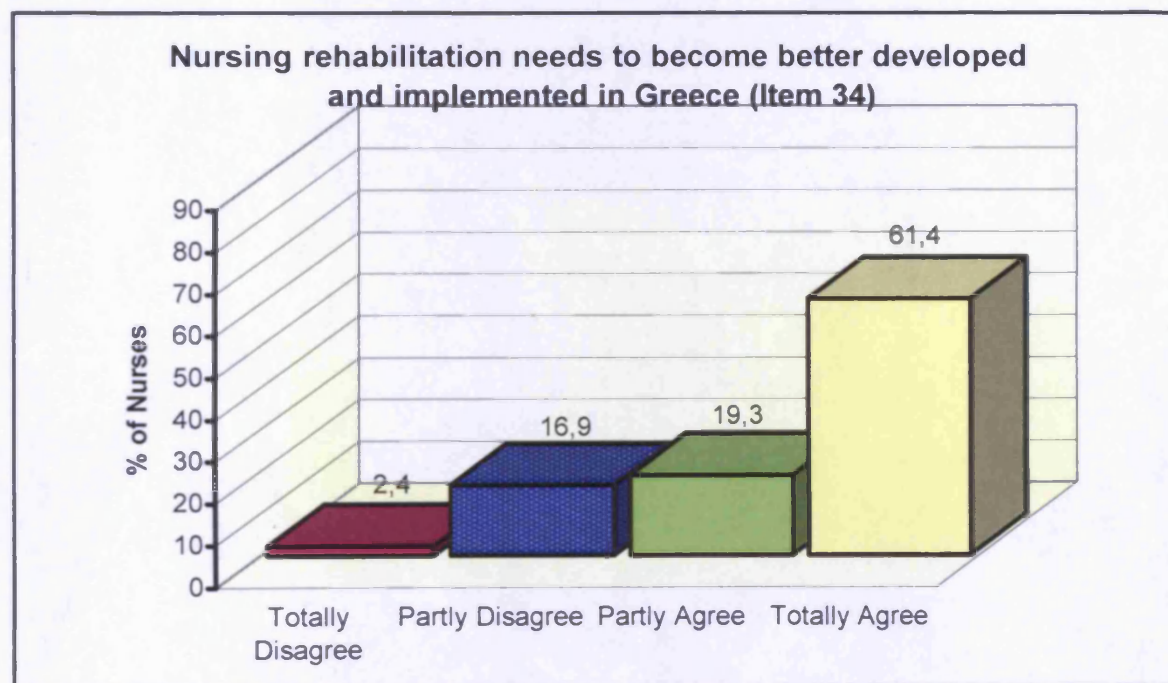


Figure 24. Nurses' Responses – Nursing rehabilitation needs to become better developed in Greece (Item 34)

**Appendix IX. Chi-square and Fisher's Exact Test Findings:
Comparison of Parents' and Nurses' Responses**

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Comparison between Parents' and Nurses' Responses

QUESTIONS		Parents n=103		Nurses n=83		X ²	p
		Disagree	Agree	Disagree	Agree		
1	It is more demanding to care for a child with CHP or disabilities than caring for a healthy child.	2 (1.9%)	101 (98.1%)	4 (4.8%)	79 (95.2%)		>0.05*
2	I (<i>parents</i>) often feel depressed while caring for my child who has a CHP or disability.	20 (19.4%)	83 (80.6%)	13 (15.7%)	70 (84.3%)	0.22	>0.05
3	Parents of children with CHP are the sole participants in their child's care	56 (54.4%)	47 (45.6%)	1 (1.2%)	82 (98.8%)	58.65	<0.001
4	I (<i>parents</i>) have faced many problems in learning how to successfully care for my child's condition.	2 (1.9%)	101 (98.1%)	3 (3.6%)	80 (96.4%)		>0.05*
5	Rehabilitation programmes should be developed for children with CHP or disabilities.	2 (1.9%)	101 (98.1%)	0 (0.0%)	83 (100.0%)		>0.05*
6	Parents support groups bring positive results in helping parents cope with their child's health problem.	12 (11.7%)	91 (88.3%)	22 (26.5%)	61 (73.5%)	5.83	<0.05
7	I (<i>parents</i>) believe that my (<i>their</i>) child is accepted by society.	34 (33.0%)	69 (67.0%)	68 (81.9%)	15 (18.1%)	42.46	<0.001
8	My child (<i>these children</i>) can successfully care her/himself.	28 (27.2%)	75 (72.8%)	49 (59.0%)	34 (41.0%)	17.93	<0.001
9	Nursing staff members have often offered support and encouragement concerning my child's condition	56 (54.4%)	47 (45.6%)	3 (3.6%)	80 (96.4%)	52.35	<0.001
10	Nurses have suggested other treatment regimes when one method has failed.	59 (57.3%)	44 (42.7%)	0 (0.0%)	83 (100.0%)	67.01	<0.001

11	Nurses have encouraged me to plan for a productive future for my child.	70 (68.0%)	33 (32.0%)	4 (4.8%)	79 (95.2%)	73.88	<0.001
12	My child's (<i>these children</i>) condition could have been prevented.	54 (52.4%)	49 (47.6%)	31 (37.3%)	52 (62.7%)	3.62	>0.05
13	Nurses have offered support to my family and me over a long period of time.	66 (64.1%)	37 (35.9%)	1 (1.2%)	82 (98.8%)	76.13	<0.001
14	Children with chronic health problems should go only to special schools and not public schools.	75 (72.8%)	28 (27.2%)	23 (27.7%)	60 (72.3%)	35.72	<0.001
15	Nurses have not encouragement me to send my child to a public school.	0 (0.0%)	103 (100.0%)	1 (1.2%)	82 (98.8%)		>0.05*
16	Nurses should offer me information even if it is discouraging.	4 (3.9%)	99 (96.1%)	1 (1.2%)	82 (98.8%)		>0.05*
17	Parents should have the right to withhold information about their child's illness from their family and friends.	26 (25.2%)	77 (74.8%)	19 (22.9%)	64 (77.1%)	0.04	>0.05
18	I (<i>parents</i>) expect encouragement and hope from nurses concerning my child's health problem.	11 (10.7%)	92 (89.3%)	4 (4.8%)	79 (95.2%)	1.41	>0.05
19	It often helps me (<i>parents</i>) feel better by talking to other parents about our children's health problems.	4 (3.9%)	99 (96.1%)	18 (21.7%)	65 (78.3%)	12.31	<0.001
20	I (<i>parents</i>) often think about the nurses who have cared for my child.	55 (53.4%)	48 (46.6%)	25 (30.1%)	58 (69.9%)	9.23	<0.01
21	Nurses appear to feel uncomfortable when talking to me about my child's diagnosis.	31 (30.1%)	72 (69.96%)	26 (31.1%)	57 (68.7%)	0.03	>0.05
22	Physicians are the only qualified persons to offer information to me concerning my child's condition	15 (14.6%)	88 (85.4%)	28 (33.7%)	55 (66.3%)	8.46	<0.01
23	It is the nurses' role to evaluate how well my child and family are adjusting.	78 (75.7%)	25 (24.3%)	19 (22.9%)	64 (77.1%)	49.32	<0.001
24	Nurses should attempt to answer our questions since they are well enough informed.	80 (77.7%)	23 (22.3%)	59 (71.1%)	24 (28.9%)	0.74	>0.05

25	When dealing with the parents, nurses do not need to understand the grieving process since the parents have not lost their child to death.	16 (15.5%)	87 (84.5%)	28 (33.7%)	55 (66.3%)	7.45	<0.01
26	Children with CHP often feel inadequate and lack self esteem.	43 (41.7%)	60 (58.3%)	18 (21.7%)	65 (78.3%)	7.51	<0.01
27	Nurses should encourage parents to plan for their child's future and encourage independence at every opportunity.	12 (11.7%)	91 (88.3%)	0 (0.0%)	83 (100.0%)	8.5	<0.01
28	Nurses need to provide us (<i>parents</i>) with up to date information for possible future health problems.	64 (62.1%)	39 (37.9%)	3 (3.6%)	80 (96.4%)	65.79	<0.001
29	Nurses (<i>I</i>) visited my (<i>childrens'</i>) home and offered me support.	95 (92.2%)	8 (7.8%)	80 (96.4%)	3 (3.6%)		>0.05*
30	I (<i>parents</i>) often feel periods of sorrow and depression having felt the loss of my "perfect" child.	10 (9.7%)	93 (90.3%)	6 (7.2%)	77 (92.8%)	0.11	>0.05
31	I (<i>parents</i>) often experience joy and happiness from their child.	19 (18.4%)	84 (81.6%)	41 (49.4%)	42 (50.6%)	18.76	<0.001
32	I (<i>parents</i>) feel happy when I see the nurse interacts with my child.	11 (10.7%)	92 (89.3%)	1 (1.2%)	82 (98.8%)	5.36	<0.05
33	Nursing rehabilitation is very important for my child.	2 (1.9%)	101 (98.1%)	12 (14.5%)	71 (85.5%)	8.62	<0.01
34	Nursing rehabilitation should be well developed and implemented in Greece.	20 (19.4%)	83 (80.6%)	16 (19.3%)	67 (80.7%)	0.001	>0.05
35	Nursing rehabilitation should be based on personal needs.	29 (28.2%)	74 (71.8%)	28 (33.7%)	55 (66.3%)	0.44	>0.05
36	Nursing care and rehabilitation should be focused more on the psychological rather than physical improvements.	19 (18.4%)	84 (81.6%)	11 (13.3%)	72 (86.7%)	0.57	>0.05

Appendix X. Decision Trail and Audit Trail of one Theme

Appendix X. Audit trail of one theme. Raw data, categories and theme.

Parent's Quotes	Categories based on Parent's Quotes	First suggested theme	Themes
<p><i>"I pray that he will not be on crutches when he is 18 years old! We believe in miracles and according to our child's illness we chose which saint to pray to."</i></p> <p><i>"After I tried to commit suicide I received psychiatric care which has helped me to feel more comfortable now thanks to my renewed faith in God!"</i></p> <p><i>"Faith is very important and I pray often for my child to regain her health."</i></p> <p><i>"My husband and I discussed the possibility of abortion, but we could not go through with it because it is against our religion. Now, we are so glad we didn't!"</i></p> <p><i>"I make "tamas" (promises) to the Virgin Mary to help her."</i></p> <p><i>"Every year I take my daughter to Tinos, since it's church there is known for its miracles"</i></p>	<p><i>I pray that he will not be on crutches ...</i></p> <p><i>We believe in miracles...</i></p> <p><i>We chose which saint to pray to...</i></p> <p><i>Renewed faith in God...</i></p> <p><i>"Faith is very important... I pray often for my child..."</i></p> <p><i>Abortion... is against our religion.</i></p> <p><i>"I bargain with God".</i></p> <p><i>"Faith in miracles".</i></p>	<p style="text-align: center;">"Religion"</p> <p>(Through further reflexion it was decided that these statements were not necessarily concerning religion but they all had in common their indication of their "faith" in their religion. Thus, the theme was re-named.)</p>	<p style="text-align: center;"><i>"Our faith helps us...."</i> <i>(The meaning of these statements indicate not the significance of the formal "church" and religion but of how these participants' perceptions of their faith in God, which they felt, helped them cope better.)</i></p>

Decision Trail

Qualitative Portion

<p>Topic chosen- original-popular due to Greece hosting Para-Olympic Games-special interest since I have friends with Chronic health problems(CHP) such as arthritis-MS-diabetes</p>	<p>Literature review was done to explore the concepts and findings of other studies-this was written with King's Conceptual Framework as a guide</p>		<p>Tape-recorded interviews were conducted</p>	<p>After the interviews each participant filled out the quantitative portion of the study</p>
<p>Methods reviewed in order to chose which one to use to obtain the aim and goals of the study</p>	<p>Irrelevant methods were rejected</p>		<p>Pilot Study of interviews was done</p>	<p>No changes needed to be made</p>
<p>Triangulation method was chosen to enhance credibility of findings</p>	<p>Two types- qualitative and quantitative data included two sources- nurses and parents of children with CHP</p>		<p>Analysis began immediately-Transcribed the interviews</p>	<p>Transcripts were read while listening to the recording-feelings noted-non-verbal language remembered</p>
<p>Semi-structured-interviews- Interviews chosen in order to allow participants to include other topics but would</p>	<p>insure the topics of interest to the study to be included- Interviews lasted for a long time which enhances credibility</p>		<p>Topics were noted- included behaviours, feelings, roles, relationships</p>	<p>Topics were organized into themes and categories-there was a constant revision of these throughout the study as new transcripts were added</p>
<p>Research questions planned as reference for researcher to cover at least the topics of the questionnaires in order to</p>	<p>Purposive sample chosen since experience in dealing with the phenomenon was needed-also Byrnes claim this adds to credibility of study</p>		<p>Categories were named, defined, discussed and examples were included from the transcripts</p>	<p>The importance was decided from the high frequency of reports made-patterns were identified-</p>
<p>Sample size not chosen at first since some authors suggest to continue until data saturation-the most articulate participants of the quantitative sample as suggested by Morse</p>	<p>Interviews beyond saturation adds reliability if the addition interviews reinforce the original ones thus, 30 Nurses (N)and 30 Parents(P) were included Two nurses refused</p>		<p>Themes were identified and thick descriptions were maintained since these descriptive elements add to transferability(Hewitt-Taylor,2001)</p>	<p>Member checks were conducted which resulted in no need for changes which increased the trustworthiness of the findings</p>
<p>Appointments made with the proper authorities to obtain access to participants-ethical permission was granted from them Parents were contacted by the authorities and permission for the</p>	<p>researcher to visit them was requested-home or office for better interviews Nurses were asked by the researcher to join the study-conducted in private room on premises</p>		<p>Each transcript was divided and phases were colour coded with highlighters according to themes</p>	<p>Reading and rereading for clarification was carried out</p>
<p>"Bracketing" to prevent researcher from projecting into interviews- journal for self-awareness</p>	<p>I was the tool-but needed to "hear" their lived experience otherwise findings would be meaningless</p>		<p>Writing up- using King's Conceptual Framework In-depth descriptions of a few families were included after the demographics were provided .</p>	<p>The themes from the parents interviews were provided followed by the nurses' demographics and the themes from their interviews</p>
<p>Ethical consideration each participant was informed that confidentiality would be maintained, they could stop at any time-verbal consent given.</p>	<p>appointments were made for the interviews to take place in their home or office since this is conducive to a better interview</p>		<p>Discussion- included all the relevant lit. and qual & quantit findings and recommendations. In this chapter all of the gathered finding were presented along with their meanings</p>	<p>The conclusion covered the highlights and summary of findings- The references were presented and a Decision Trail was included in the Appendix.</p>